

Digital Dialogue:

An Analysis of Social Media Access for People with Developmental Disabilities

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■ Preamble

CanAssist is delighted to have the opportunity to act upon the leadership of Community Living BC's vision regarding the opportunities and challenges associated with social media for the individuals whom they serve. We believe that the CLBC-sponsored Social Media Feasibility Study makes a contribution to better understanding the challenges and opportunities associated with social media access and usage for individuals with developmental disabilities.

CanAssist, based at the University of Victoria, has been in existence for over a decade and is dedicated both to increasing inclusion in society for those with special needs and to addressing unmet community needs. We work to achieve this by developing innovative and empowering technologies and programs that promote independence and improve the quality of life of our clients. For more information about CanAssist please visit our website at www.canassist.ca

CanAssist's proven track record reflects the following core strengths:

- A highly talented and diverse interdisciplinary team;
- A broad range of projects;
- Innovative research and technology development;
- Extensive community outreach and service;
- A strong focus on education and experiential learning; and
- A high level of integration into the university.

CanAssist has gained unique experience as a result of the strengths outlined above and this experience has been utilized in all aspects of conducting the feasibility study. This is reflected throughout the commentary in the literature review, the analysis of the survey results and focus groups, and the recommendations associated with the report.

I would like to acknowledge the multi-disciplinary team who shared in completing the study. The team members are Luke Melchior, Leo Spalteholz, Robin Syme, and Kristen Kay. Please refer to Appendix C for a brief description of what each of these team members brings to this project.

We are confident that the BC disability community will continue to lead the way with respect to inclusion and that collectively we have the vision, leadership, and expertise to ensure that social media are accessible to British Columbians living with developmental disabilities.

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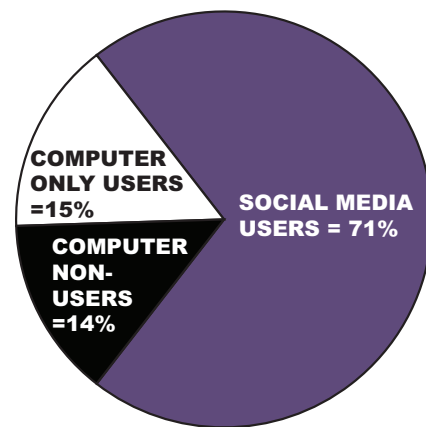
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■ Executive Summary

In less than a decade, social media platforms have replaced television as the most popular venues for media consumption. Currently 81% of Canadians aged 18 to 34 have a social networking account and the numbers continue to grow daily.

In March 2010, Community Living British Columbia (CLBC) commissioned CanAssist at the University of Victoria to undertake a social media study regarding social media accessibility and its usage for individuals with developmental disabilities.

The study includes a literature review; an online survey completed by 214 respondents representing individuals with developmental disabilities, including self-advocates, family members and caregivers; and 10 in-person focus groups with a total of 117 participants. Collectively over 300 individuals were involved in providing feedback regarding social media access and usage. The results of the survey indicate that 71% of those individuals use social media to some degree, 15% use computers for basic functions only, and 14% don't use computers.



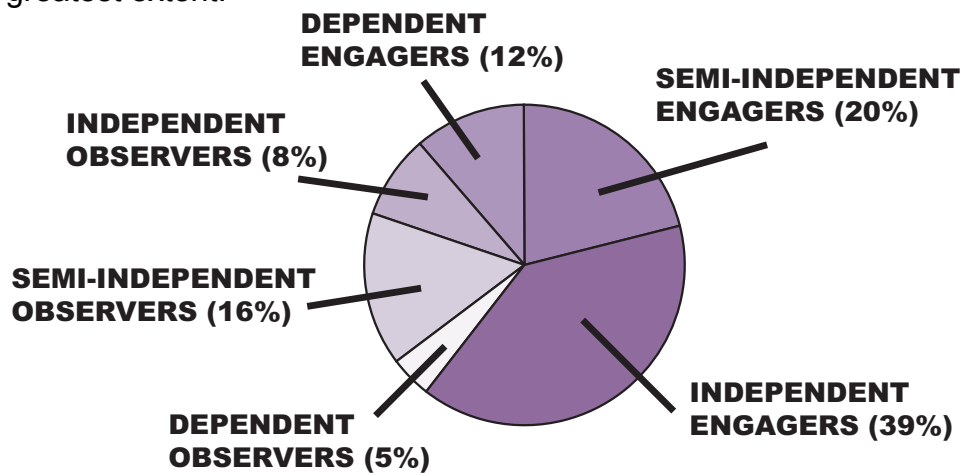
Both the literature review and consultative process confirmed that social media usage has the potential to significantly further the inclusion and societal contributions of those living with disabilities and, more specifically, those individuals with developmental disabilities.

Social media creates new space for people with developmental disabilities to interact with family and friends, make new friends, and connect with the broader community. Access to social media has the potential to help address isolation and loneliness for our most vulnerable citizens.

Social media is emerging as an important and unique vehicle for people with developmental disabilities to control the expression of their own ideas and concerns and, as a result, promote self-advocacy and “smash” stereotypes. It is a “social equalizer” (Chapman, 2010).

To date, CLBC and other BC leaders in disability endeavours have demonstrated that the benefits of thoughtful innovations that maximize independence and realize self-direction and citizenship outweigh any associated risks and, equally importantly, that these risks can be effectively managed with a “conscionable amount of vigilance” (Kendrick, 2005, p.9).

Our study revealed that individuals with developmental disabilities use social media to varying degrees, governed primarily by their level of independence when using computers and their level of engagement. As a result of these findings, participants were assigned to one of six clusters: dependent observers (5%), semi-independent observers (16%), independent observers (8%), dependent engagers (12%), semi-independent engagers (20%), or independent engagers (39%), where independent engagers were using social media to the greatest extent.



Some key additional findings are that:

- Literacy is the most commonly reported challenge for people with developmental disabilities, and presents the biggest barrier to accessing mainstream social media.
- Both self-advocates and support persons see social media platforms as important venues for communication.
- Self-advocates report that access to mainstream social media platforms is more important to them than access to specialized (i.e. disability tailored) platforms, and that the benefits outweigh potential risks.
- While families and caregivers voice privacy and safety concerns, they also acknowledged that access to mainstream social media platforms is as important as access to specialized platforms for people with disabilities.
- Currently, Facebook is inaccessible for many and yet it is “the social media of choice” for self-advocates and others with developmental disabilities.
- The release of developer interfaces for large social media platforms makes it possible to create alternate front-ends to these websites, which make them more accessible to individuals with developmental disabilities.

- Trained online buddies, ideally self-advocates who are social media savvy, would be a useful support option for peers who require social media training, along with ongoing technical, social-etiquette, and/or safety supports.

In light of this study, we offer the following recommendations:

Primary

1. BC agencies should continue to demonstrate leadership in embracing social media, furthering research into social media issues for persons with disabilities, and encouraging the use of social media platforms for communication.
2. Create plain-language educational and support materials about social media targeted at persons with disabilities, their families, and their caregivers.
3. Create an interactive social media safety assessment tool to assess users as to their knowledge and ability to operate safely on social media.
4. Develop an accessible Facebook interface, designed to address issues unique to persons with developmental and physical disabilities.
5. Undertake a pilot project to implement a buddy or support system around social media that would engage self-advocates and directly address concerns regarding security and privacy

Secondary

1. Develop an accessible survey tool for performing qualitative surveys of people with developmental disabilities, especially those with literacy challenges.
2. Continue conducting research to better quantify and understand the effects of social media use by persons with developmental disabilities.
3. Compile a set of accessibility guidelines for websites to be usable by persons with developmental and physical disabilities.
4. Focus on the development of tools that provide users with the opportunity to more actively participate in social media.

In conclusion, the study and accompanying recommendations indicate that, with the appropriate tools and supports in place, mainstream social media platforms can be extraordinarily valuable vehicles for empowerment and inclusion, and should be truly accessible and available to individuals with developmental disabilities. BC has a unique opportunity to take a leadership role in promoting and implementing work to make social media truly accessible and available to individuals with developmental disabilities.

Introduction

Report Focus

The purpose of this report is to examine the accessibility of social media for people with developmental disabilities. While there are many adaptations and interface considerations for persons with physical and vision-related disabilities, the approaches and solutions to these problems are almost purely technical, and have received significant attention in research and existing social media implementations. Very little attention has been paid to opening up traditional social media tools to persons with developmental disabilities.

Project Goals

The goals of this feasibility study were to:

1. Describe the various web-based social media/social-networking platforms that are currently available, along with the current and expected trends across this industry.
2. Determine the degree of accessibility of these platforms to Community Living BC (CLBC) clients, along with the reasons for this accessibility, or lack thereof.
3. Determine what would be required—as to technical and/or other supports—to make such platforms more accessible to CLBC clients.

Literature Review

This report features a literature review organized according to a social media access process developed for the project. The process, shown in Figure 1, reflects the basic motivations, skills, knowledge, and technologies/tools required for a person with a developmental disability to successfully utilize social media.

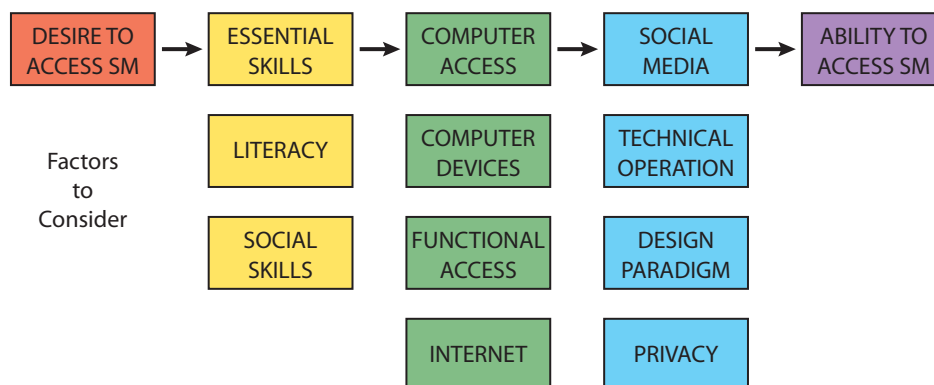


Figure 1: Social media access process for people with developmental disabilities

Survey and Consultations

This report also features the results of a survey and a number of focus group consultations conducted by CanAssist. These were designed to meet the following goals:

- 1. To solicit direct feedback from self-advocates, persons receiving CLBC services, families, and CLBC contracted service providers concerning:**
 - Existing social relationships
 - Knowledge and awareness of social media platforms
 - Social media intentions, preferences, and current usage patterns
 - Accessibility of various social media platforms
 - Barriers to access and usage

- 2. To identify social media platforms that are either already accessible or could be made to be more accessible through customized modifications.**

■ Desire to Access Social Media

What is “Social Media”?

According to Kaplan and Haenlein (2010), social media refers to the group of applications and websites on the Internet where computer device users from all over the world can participate in and collaborate on creating live media content. Kaplan and Haenlein identify six distinct types of social media: collaborative projects, blogs, content communities, social networking sites, virtual game worlds, and virtual social worlds.

Collaborative projects (e.g. Wikipedia) allow users to jointly create and modify content at the same time, and **content communities** (e.g. YouTube) allow users to share media content with one another. **Blogs** (e.g. Blogspot) are websites that feature time-stamped entries written by a particular user that include the option for readers to post feedback.

Virtual game and social worlds represent the most sophisticated type of social media. They are three-dimensional environments where users, represented by personalized characters, can interact with one another in a gaming (e.g. World of Warcraft) or social (e.g. Second Life) context.

The final and perhaps most popular type of social media is the **social networking site**. Applications like Facebook “enable users to connect by creating personal information profiles, inviting friends and colleagues to have access to those profiles, and sending e-mails and instant messages between each other” (Kaplan & Haenlein, 2010).

For the purpose of this study, we will focus on social networking websites such as Facebook and Twitter, and content communities like YouTube. These forms of social media are by far the most widespread and popular.

Why is Social Media Important?

Trends in Social Media Usage

Research by Fleishman-Hillard (2010) reveals that the Internet has now surpassed television as the most popular source of media consumption among Canadians. In fact, Canadians lead the world in social media usage (Marcusa, 2010). According to Ipsos Reid (2010), 52% of all Canadians have visited YouTube and 41% (and 81% of those aged 18 to 34) have an online social networking profile.

Trends in Social Media Usage (continued)

Two recent surveys have shown similar findings for people with disabilities. The 2010 CanAssist Social Media Survey (see Survey and Consultations section on page 24) found that 57% used YouTube and 49% used Facebook, while the 2010 Easter Seals Living with Disabilities Study indicated that 55% had used Facebook or similar social networking websites (Easter Seals, 2010).

Social Media Platforms Promote Communication, Connection, and Belonging

Many people with developmental disabilities do not have any contact with their families, have no friends, and instead depend on people who are paid to be with them (Pitonyak, 2010). Pitonyak believes that these individuals are profoundly lonely, and that much of their suffering results from isolation, not disability. People who are lonely have a lower sense of self worth, are less likely to have other people to whom they can turn for assistance, are exposed to stressful events more frequently, and have higher blood pressure on average than non-lonely individuals (Cacioppo, Hawkey, & Bernston, 2003). "We are relational beings and the absence of meaningful relationships makes us sick" (Pitonyak, 2010).

Pelletier (1994) agrees: "A sense of belonging appears to be a basic human need—as basic as food and shelter. In fact, social support may be one of the critical elements distinguishing those who remain healthy and those who become ill" (p. 137). When people are connected to a social network, they are generally happier, healthier, and better able to adjust to life's ups and downs (Pitonyak, 2007). A nine-year California study found that people with many social contacts lived longer and had better health than those who were socially isolated (Hafren, Karren, Frandsen, & Smith, 1996).

Belonging to One Another: Building Personal Support Networks, a CLBC publication (CLBC, 2009), states that having people you care about, and who care about you, in your life is one of the most important ways to feel safe, valued, and connected. It highlights the difference between inclusion (being in) and belonging (being part of), and how our connections to others support a sense of belonging and avenues for community integration. For people with developmental disabilities, belonging results in greater community involvement, increased life satisfaction, and better self esteem (CLBC, 2009).

To foster an increased sense of belonging, many are now turning to social media. Social media platforms provide opportunities for people with developmental disabilities to meet new people and spend time with friends and family, which is especially important for individuals who are isolated either geographically or due to the limitations of a disability (CLBC, 2010). As one community inclusion organization representative put it, "They communicate with each other on Facebook Then, they can make friends with other people's friends the way the rest of us do ... it's a social equalizer in a way" (Chapman, 2010).

Social Media Platforms Promote Communication, Connection, and Belonging (continued)

Social media success stories are becoming more commonplace for people with developmental disabilities. One article describes how Facebook played a part in one woman's transition from living in a highly supervised group home to getting a job and moving into her own apartment (Chapman, 2010). Another story discusses how a woman used Facebook to receive support from others whenever she felt upset or lonely (CLBC, 2010).

Social media platforms have created a new space for people with developmental disabilities to interact with the broader community and control the expression of their own concerns, thus promoting self-advocacy and helping to "smash" stereotypes (Ignagni & Abbas, 2008). Two social media efforts that have been created in this new space include *Spread the Word to End the Word*¹ (a campaign to end the use of the "R" word), and *Not Dead Yet*² (an anti-euthanasia blog in support of people with significant disabilities).

History of Social Media

One might regard the first publicly accessible form of social media as the Usenet system, introduced in 1979. Usenet was "a worldwide discussion system that allowed Internet users to post public messages" (Kaplan & Haenlein, 2010). While it was not known as social media at the time, this system contained mostly user-created content. However, in part due to the fact that Internet access was still largely limited to academic institutions and businesses, the public did not use this system in large numbers. Not until the advent of the World Wide Web in 1991 were the seeds planted for social media's success. From that point on, the number of Internet users grew exponentially (Quittner, 1999).

For the first 12 years, however, the World Wide Web largely consisted of web pages created by individual users and published for others to read. Websites were essentially read-only, and did not allow users to interact with or modify the content. It wasn't until social networking websites like MySpace and Facebook were developed (in 2003 and 2004 respectively) that continuously updated content created by many users would become the norm. The social media phenomenon had re-emerged and was now, once and for all, here to stay (Kaplan & Haenlein, 2010).

¹ <http://www.r-word.org>

² <http://notdeadyetnewscommentary.blogspot.com>

■ Essential Skills

Literacy

Internet-based media require reading and writing skills at a level often higher than for traditional media (Collins, Onwuegbuzie, & Jiao, 2008; Bohman, 2010; Kemp & Bushnell, 2011). The reader needs to be able to scan for relevant information from amongst a lot of “noise,” decipher text blocks of greatly varying lengths, understand writing styles with significant quality differences, and comprehend many societal references (Bohman, 2010).

Further complicating the terrain of both reading and writing in social media is the emergence of a writing style called “textese” that now appears in text messages and in Facebook and Twitter posts. Kemp and Bushnell (2011) describe textese as an English-language hybrid that was created to increase the efficiency of text messaging. More specifically, they define it as a sound-based spelling style featuring “common abbreviations, or *textisms*, [including] letter and number homophones (*c* for *see*, *2* for *to*), contractions (*txt* for *text*) and non-conventional spellings (*skool* for *school*)” (Kemp & Bushnell).

While it may appear counter-intuitive, Kemp and Bushnell (2011) have shown that high literacy skills are required in order to effectively communicate using textese. They point to a variety of studies that have demonstrated to differing extents that textese proficiency depends on skills related to verbal reasoning, word reading, sound-letter awareness, and spelling.

For those with literacy challenges, traversing this new digital landscape will be vital if they are to avoid being left behind. In the case of textese, the social media “language” used by one’s peers may be a prerequisite for membership in their social groups (Kemp & Bushnell, 2011). And at a more basic level, a person’s literacy level may impact their computer experience so much so that it may cause them to abandon computers altogether (Collins et al., 2008).

Social Skills

Why They Are Important

While social media platforms represent methods of communication, they still require the same basic social skills as other forms of communication in order to be used effectively. In fact, given the potential for misunderstandings in the short, text-based messages that are typical on social media, these skills may even be more important to possess when communicating online. According to Gresham, Sugai, and Horner (2001), when people develop effective social skills, they become better able to “establish and maintain satisfactory interpersonal relationships, gain peer acceptance, establish and maintain friendships, and terminate negative...interpersonal relationships” (p. 331).

However, as Morgan (2010) asserts, if a person has any type of underlying behavioural disorder (for example), developing such skills could be a challenge. Barriers for this population may include aggression, impulsivity, or a lack of coping ability. They may need targeted training in certain social skills in order to participate in social media.

Skills That Require Mastery

Morgan (2010) suggests that social media users need to employ at least five essential social skills. First, they need to know how to have a basic conversation so that they can introduce themselves to people, chat, or post messages. Secondly, it is important to know how to express feelings in a respectful manner. Third, users need to know how to avoid trouble with others (e.g. no taunting, teasing, threatening).

Morgan's fourth and fifth essential skills involve protecting social media users from potentially dangerous situations. The fourth skill is being able to respond to negative persuasion from peers or strangers who may, for example, want the user to post inappropriate pictures or engage in inappropriate conversations. The final skill is the ability to make appropriate decisions when faced with a choice (e.g. whether or not to attend a party).

Morgan (2010) proposes that these social skills can be taught effectively through modeling, role-play, or games. Modeling often involves acting out a situation where appropriate behaviour is demonstrated. After a behaviour has been modeled, a good next step would be to role-play a similar scenario where the learner would have the opportunity to practice the behaviour. Finally, the learner could play a game where they are rewarded for responding appropriately to a situation presented to them.

Computer Access

Computer Devices

While traditional desktop and laptop computers are still the dominant means by which Canadians access social media, mobile technologies are beginning to take hold. As of 2010, 21% of Canadians used a smartphone for Internet access (Ipsos Reid, 2010). For people with developmental disabilities, the number was 13%, according to the 2010 CanAssist Social Media Survey.

Kaplan and Haenlein (2010) estimate that “by 2020, a mobile device will be the primary Internet connection tool for most people in the world” (p. 67). If so, this means that more and more Canadians will want to access social media from a mobile device over the coming years. As Swan (2008) points out, people with disabilities are no exception: “Users with disabilities ... also have multiple devices and want to connect to their social networks of choice across these devices” (p. 1).

This trend is beginning to pose a problem for the accessibility of social media tools. Since resources are limited, the adaptations to technology for those with disabilities are often one step behind the state of the art (Swan, 2008). For example, while many effective tools have been developed to make simple web pages, email, and instant messaging accessible to people with disabilities, support for modern dynamic web pages and mobile devices is generally still poor. In addition, the physical size of buttons and text on mobile devices pose problems for those with disabilities related to dexterity or vision. There are no standards for assistive input devices amongst phone manufacturers, and the rapid pace of device evolution has prevented the development of generally useful alternate input devices.

The lack of access to mobile phones is especially problematic given the ever-increasing number of new, mobile-specific social media applications. To further complicate matters, the software on most mobile devices is closed to outside developers, which precludes the kind of far-reaching modifications to the user experience that are often necessary to increase accessibility for different user groups.

Functional Access

Basic Web Function Access

Choosing the optimal assistive technology (AT) solution to enable social media access for a person with a significant disability is often a complex endeavour, and beyond the scope of this report. However, there are general web access functions that must be accessible to a user to enable independent navigation of social media:

1. *Accurate pointer control.* Many assistive technology devices control the mouse pointer in some fashion, including head mice, joysticks, eye trackers, and trackballs. However, users must have sufficiently accurate control of their input device to target small links on-screen, which are common on complex social media platforms like Facebook (Figure 2).
2. *Web-compatible text entry method.* The chosen text-entry method for a given input device must be compatible with the dynamic nature of social media platforms.
3. *Method for reading text on social media platforms.* For people with literacy or visual disabilities, software such as screen readers and highlighting readers are available to improve access to text content. However, compatibility of this software with dynamic websites and complex layouts is poor, posing a significant challenge to accessing social media for persons with such disabilities.



Figure 2: Small link targets on Facebook. Links are highlighted.

Internet Access

Broadband, or high-speed, Internet access is fairly widespread in Canada. Fifty-nine percent of Canadians now have a high-speed connection at home, compared to only 22% who still rely on a much slower dial-up connection, and 14% who have no access to the Internet at all (Ipsos Reid, 2010)³.

This may sound promising on the surface; however, since most forms of social media require a broadband Internet connection in order to function optimally, more than one-third of Canadians are at a distinct communication disadvantage. Parsons and Hick (2008) agree: “Exclusion, lack of up to date technology and the inability to afford Internet services increasingly threatens the chances of many people to ... participate in the affairs of the broader society” (p. 4).

The Federal Government is currently working to expand broadband connectivity for rural Canadians through an Industry Canada initiative called *Broadband Canada*. On the Broadband Canada website, the Government affirms the importance of this technology:

“Broadband internet access is viewed as essential infrastructure for participating in today's economy, as it enables citizens, businesses and institutions to access information, services and opportunities that could otherwise be out of reach.”
(Industry Canada, 2010)

³ The numbers were much higher for the people with developmental disabilities from the 2010 CanAssist Social Media Survey: at home, 85% had a high-speed connection, 3% had dial-up, and 4% had no connection.

■ Social Media

Accessing Existing Websites

Before discussing how to increase the accessibility of social media for people with disabilities, it is important to begin by looking at the accessibility currently offered by the major social media platforms, namely Facebook, YouTube, and Twitter.

Facebook

As with most sites, Facebook requires users to complete a test called a CAPTCHA (Completely Automated Public Turing test to tell Computers and Humans Apart), in order to become a registered user (see page 16 for a full description). While Facebook (2010) promotes this as being accessible since it offers an audio alternative, American Foundation for the Blind (AFB) staffer Ingber (2009) points out that the audio is difficult to understand. When a user selects “an audio captcha,” the screen changes from the screen on the left of Figure 3 to the screen on the right. A female voice then says, “Please type every word you hear with a space between each word. Don’t worry if you have trouble with some words; just enter your best guess.” These instructions are followed by an obscure 10-word audio clip, typically selected from an old movie or television show.



Figure 3: The Facebook CAPTCHA

Ingber (2009) also mentions other challenges that Facebook users with vision-related disabilities (or literacy challenges) must overcome. The biggest issue concerns web page clutter: “this can be confusing and cumbersome to navigate” (Ingber). Another issue is that the accessibility of third-party applications varies considerably. A third issue involves the Chat feature; it is extremely difficult to use with a screen reader due to the page reloading as well as message placement. The (WebAIM, 2009) survey found that over 40% of screen reader users had difficulties accessing Facebook.

Facebook (continued)

Despite these shortcomings, Facebook has made at least two useful accessibility improvements. First, the company now has a basic version⁴ of its website that was originally designed for use on mobile phones but also works well for users who find page clutter challenging or use a screen reader (Facebook, 2010). The basic version presents all information from top to bottom with no advertisements. Secondly you can now access Facebook Chat through your instant messaging software of choice (Reiss, 2010). This means that people with disabilities (who are comfortable with instant messaging) have the opportunity to chat with their Facebook friends using a more accessible chat program.

YouTube

The audio CAPTCHA currently used during the YouTube registration process is the same one that Facebook once used. Ingber (2009) describes this CAPTCHA as having "... a lot of background noise and ... numbers are spoken by various, sometimes hard-to-understand, voices" (Registration, para. 1). In addition, no audio instructions are given. Registration is required in order to post videos or create a playlist.

In addition to the problematic registration process, the standard YouTube site suffers from at least two other major accessibility flaws. The first flaw is the use of Adobe Flash to display and play videos. Ohio State University (2010) reports that most browsers do not support keyboard-only control of Flash objects and "screen [readers] ... cannot always accurately discern the function of [Flash controls], and some screen readers cannot access Flash controls at all" (Accessible Controls for the YouTube Embedded Video Player, para. 1). The author goes on to assert that controls in the web page itself would be an effective alternative.

The second YouTube accessibility flaw involves the video control options themselves—they pose considerable challenges to people with developmental disabilities. For example, there is no clear separation between the video and the controls, the controls are too small and ambiguous, and there is no option to repeat the playing of the video (Hyde, 2009)⁵.

To overcome many of these barriers, YouTube users have two options: they can either use the mobile version⁶ of YouTube or they can try Easy YouTube⁷. The mobile YouTube site is stripped of extra columns and advertisements, and the videos play in an external viewer. Easy YouTube is even more user friendly: it provides contrasting colours and symbol-based navigation, an easy-to-resize video display, seven large-sized control buttons, and a simplified search feature.

⁴ <http://m.facebook.com>

⁵ An option to repeat video has since been added by YouTube.

⁶ <http://m.youtube.com>

⁷ <http://icant.co.uk/easy-youtube>

Twitter

The audio CAPTCHA used during the Twitter registration process is similar to the one used by YouTube but it mixes words in with the numbers and includes audio instructions. Lembrée and O'Connor (2010) identify a number of other accessibility issues on the Twitter website. These hazards include poor colour contrast (i.e. blue writing on a blue background), core functions that aren't keyboard accessible, a heavy reliance on Javascript (programming that is not always accessible to assistive technology), poor use of menus, inconsistent navigation, and the fact that links are not underlined unless the cursor is hovering over them.

With Twitter, the mobile version⁸ suffers from many of the same issues as the regular version. Users with disabilities would be much better served by a third-party version of Twitter called Accessible Twitter⁹. Accessible Twitter has good colour contrast; is fully keyboard accessible; doesn't require Javascript; uses logical, consistent menus and navigation; and underlines all links.

Technical Operation

Registration

As mentioned previously, the registration process for social media websites requires new users to prove that they are indeed human, as opposed to an automated computer program. This proof is obtained through a CAPTCHA that prompts the user to type out either a) distorted words that appear in an accompanying image, or b) a spoken phrase, words or numbers that can be accessed by clicking a sound icon.

As Babinszki (2010) states, many people with disabilities “find it difficult and sometimes impossible to pass this verification method” (para. 3). For example, if they have a cognitive or learning disability, they may not understand what they are being asked to do, discern the words being displayed, or be able to correctly spell a spoken word.

While social media websites have yet to solve these issues, Babinszki (2010) has proposed a number of viable CAPTCHA alternatives. Users could authenticate by solving a basic math problem, answering a simple question, performing an easy computer task, or by selecting a picture. Of all the options mentioned, the picture option may hold the most promise. With this method, users would be prompted to select an image from among a few choices. To accommodate visually impaired users, each image would be accompanied by an alternative description.

⁸ <http://mobile.twitter.com>

⁹ <http://www.accessibletwitter.com>

Signing in

To sign in to social media websites, users are currently required to input a text-based password. This can be problematic for users, including those with disabilities. Renaud (2004) describes this problem:

“If [a password] is hard for another person to guess, the user will probably either forget it, or record it manually If it is easy for the user to remember, then someone else will probably either be able to guess it or to break it.” (p. 18)

Having dyslexia or a developmental disability further complicates this process, making text-based passwords possibly an insurmountable barrier to social media for many users. This may be partially addressed with software tools to remember passwords on the user’s own computer, but this would not be feasible on shared or public computers.

Considering the limitations of text-based password authentication, Renaud (2004) systematically audited alternative authentication methods to see if a better solution could be found. Results indicated that a system featuring graphic recognition may hold considerable potential.

Graphic recognition typically involves the user selecting a small number of images from a larger group of images. Figure 4 shows an example of a simple graphical password. The user logs in by picking the set of images from the grid that matches the set they chose as their password.

Image sets can be remembered more easily than words, are less error-prone than traditional passwords, and are understandable to people with dyslexia. On the down side, graphical passwords take longer to set up, can be more easily observed by others when being entered, and are inaccessible to users who are blind or have a visual impairment (Renaud, 2004). However, graphical passwords could become a viable option for people with vision impairments if the images were accompanied by alternate text (Babinszki, 2010).



Figure 4: Example of a graphical password

Signing in (continued)

While the mainstream adoption of graphical passwords remains in doubt, two interim solutions have been proposed: OpenID and GPEX. Swan (2008) espoused the virtues of OpenID: “[It] eliminates the need for multiple log-ins benefiting ... disabled and older users” (p. 3). In theory, a new OpenID website could be developed for the purpose of authenticating people by means of a graphical password, allowing accessible access to any website supporting OpenID.

While none of the major social media platforms have adopted OpenID as their primary authentication method, many have added support for OpenID as a secondary account to sign in to their systems. Unfortunately, even with increased support from these providers, the envisioned accessible OpenID sign-in methods have not materialized, making the real-world improvements to accessibility via this system limited at best.

Perhaps more promising is the idea behind GPEX, a web browser plug-in that combines a password manager with a graphical password application (Bicakci, Yuceel, Erdeniz, Gurbaslar, & Atalay, 2009). With GPEX, a user creates a graphical password within a web browser (Mozilla Firefox in this case), and then this password is used to generate stronger, site-specific passwords for the various websites to which the user subscribes. The advantage of GPEX is that it doesn't require websites to modify their authentication processes in any way. GPEX is currently only a research system, running solely on the Firefox web browser. However, a similar system could be developed for other browsers.

Design Paradigms

Specialized Versus Mainstream Social Media

There are two main schools of thought when it comes to making social media more accessible to people with disabilities: create specialized social media platforms for specific groups, or create accessible interfaces that interact with existing social media.

Sillanpää, Älli, & Övermark (2010) believe that applications such as Facebook are so inaccessible to people with developmental disabilities, for example, that creating a new community-based network is the only viable solution for these users. Examples of specialized social media for people with disabilities include:

- CK Friends¹⁰ (UK) – symbol-based navigation, simple text, blog; free
- Disaboom Live¹¹ (US) – forums, blogs, chat, photo, galleries; free
- Special Friends¹² (UK) – parental controls, chat via text or pics; free
- Herbor¹³ (Denmark) – blog, calendar, life history; paid subscription
- Tyze¹⁴ (Canada) – informal case management with social media features; paid subscription.

There are two primary approaches taken by specialized social media platforms: closed and monitored, or open and unmonitored. Closed websites generally charge for access, and rely on a representative of the user to control their connections and activities on the network. Open specialized websites market to the population of persons with disabilities, but do not restrict or verify users' information when joining a network.

Specialized social media platforms present a number of advantages and disadvantages for people with disabilities. Some of these websites are adapted to meet the specific accessibility needs of their audience, with features like symbol-based navigation, simplified user interfaces, text-to-speech, or multimedia resources specific to the target disability. For example, Figure 5 compares the interfaces of Common Knowledge UK with Facebook, and shows some of these features. In the closed networks, user information and activity remains private – it cannot be viewed by non-members – and new members must be vetted by the network administrator. As Söderström (2009) discovered, the users of specialized websites "share an implicit understanding of one another's social experiences and context" (p. 721) and serve as centers of peer support and discussion.

¹⁰ <http://www.ckfriends.org.uk>

¹¹ <http://www.disaboomlive.com>

¹² <http://www.specialfriendsonline.com>

¹³ <http://www.herbor.dk>

¹⁴ <http://www.tyze.com>

Specialized Versus Mainstream Social Media (continued)

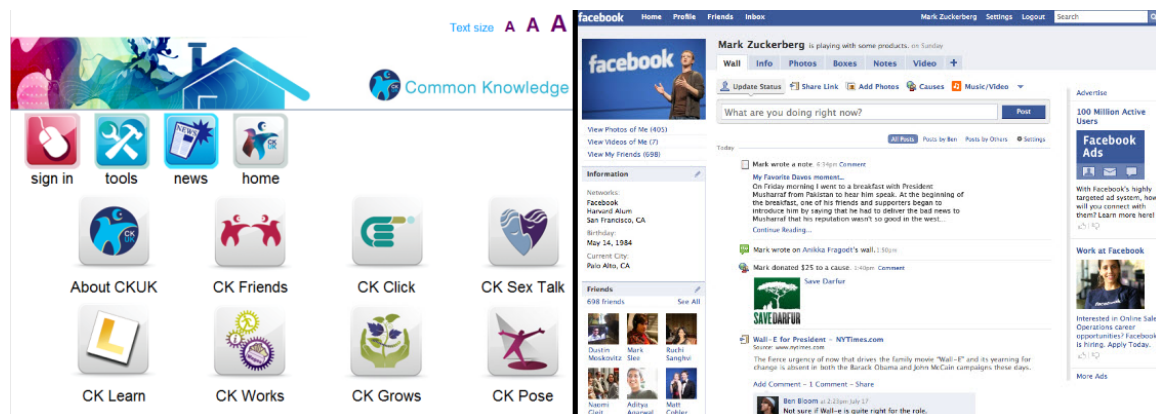


Figure 5: Comparison of visual complexity of specialized (left) and mainstream social media (right)

One disadvantage of dedicated social media platforms is that without public or philanthropic funding, these websites must be supported either by an advertising model or a user-pay model. Although reliable user statistics are difficult to obtain, Disaboom Live appears to be the largest of these networks, with a reported 19,000 monthly visitors as of September 2010 (Quantcast, 2010). However even with a relatively large user base, Disaboom Inc has not managed to profit from the site since its inception in 2007, and recent statements indicate the company is facing a very uncertain future (House, 2009). User-pay models for websites such as Herbor and Tyze may provide a more predictable support model to cover the site's operating costs, but limit the number of users to those who are willing and able to pay.

A second, and most notable, disadvantage of dedicated social media platforms is best summed up by Kelly, Nevile, Draffan, and Fanou (2008): "The danger with social networking websites which are targeted at people with disabilities is that they will not be used by one's wider circle of contacts" (p. 143).

Kelly et al. (2008) belong to the second school of thought: they propose that accessible interfaces need to be created for mainstream social media applications. They agree with their detractors that the general interfaces of popular social media are not very accessible to people with disabilities, but they feel that new interfaces can and will change this (Coltham, 2009; Dolson, 2010; Kelly et al.; Swan, 2008). Dolson (2010) points to an emerging solution:

"Almost all the major social media services offer application programming interfaces (APIs), which means that you can build practically whatever tool you need to interact with social media on your own website; and, with a good sense for accessibility issues, you can often resolve accessibility problems." (Accessibility Tools Are Not Problem-Free, para. 1)

Specialized Versus Mainstream Social Media (continued)

The discussion entitled *Accessing Existing Websites* (see page 14) mentions two accessible interfaces that were created using these APIs: Easy YouTube¹⁵ and Accessible Twitter¹⁶. The Easy YouTube interface was designed for people with developmental disabilities, with large, symbol-based controls, single function buttons, and a simplified visual design. Figure 6 compares that adapted interface to the original YouTube design. It should be noted that no accessible interfaces currently exist for Facebook.



Figure 6: Comparison of the standard YouTube interface (left) with a more accessible interface (right)

As with dedicated social media platforms, alternative interfaces to mainstream websites have advantages and disadvantages. In their favour, custom interfaces allow people with disabilities to stay connected to mainstream society. Hyde (2009) presents the following observation made by Lizzie, an Easy YouTube tester with a learning disability:

“The mainstream websites, yeah, should include people with learning disabilities. Because, though we got disabilities, we still want to keep up with the times, we still want to know what’s going on.” (para. 107)

Another advantage of accessible interfaces for popular social media platforms is the message conveyed: “This type of activity ... sends out a very clear and public message to social networks that they can, and therefore should, be made accessible” (Swan, 2008). A third advantage is the fact that a variety of interfaces could be created to meet a variety of accessibility needs. By having this choice, the social media experience could be tailored to match the unique skills and abilities of each user (Kelly et al., 2008).

¹⁵ <http://icant.co.uk/easy-youtube>

¹⁶ <http://www.accessibletwitter.com>

Specialized Versus Mainstream Social Media (continued)

Despite these promising benefits, accessible interfaces are not a panacea for addressing the accessibility challenges posed by social networks. Authentication is generally still handled by the original social media website and cannot easily be made accessible with an alternate interface, which can constitute the weakest link in the accessibility of the entire site. In addition, while an interface can control how content is presented, it cannot affect the user-generated content, which can contain inaccessible elements. Only contributors can influence the created content and the burden to make it as accessible as possible rests on them (Dolson, 2010).

It is interesting to note that current accessible interfaces have targeted mainly physical accessibility challenges and interface complexity, failing to address other considerations for users who have developmental disabilities. Concerns around security have driven the creation of specialized social media platforms for this population, with currently no attempts to add security features to an alternative interface for a mainstream social media platform.

Privacy

Facebook fuelled concerns over the privacy of social media in December 2009 when it changed its default privacy settings to make users' posts, and some profile information, public by default (Facebook, 2009). This change, and the resulting controversy over privacy of social media in general, was widely covered by the media (BBC, 2009; CBC, 2010).

Risks to Privacy on Social Media Websites

When it comes to privacy on social media websites, there are at least two areas of concern: self-disclosure and information exposure. The main risk posed by self-disclosure involves the possibility that social media users will disclose inappropriate, highly personal, or security-compromising information that could be exploited by others. Given that the level of self-disclosure largely depends on the discretion of the user, this risk could be mitigated through education for higher functioning users (which is not widely available).

The same cannot always be said for information exposure. Some aspects of information exposure are within the control of the user while others, sometimes intentionally, are not. In Facebook, for example, the user can fine-tune all the privacy settings, but since many of these settings are overly complex and features like friends lists, status updates, and comments are now set by default to be seen by everyone, unintended permissions can easily be granted. Many settings require a technical understanding of how Facebook works in order to determine the impact a setting will have (Bilton, 2010).

Risks to Privacy on Social Media Websites (continued)

Regardless of even the strictest privacy controls, limiting all content so that it can only be seen by approved friends does not guarantee that information posted to a social media website will not end up being made accessible to the public. Whether through privacy policies that allow friends of friends to see some of a user's information, friends passing on private information, or an account being compromised by a third party (McMillan, 2010), everything on a social media website should be considered to be public information.

It should be noted that although there are problems with the permissiveness of social media websites, many of these websites give very fine-grained control over how much information will be revealed and to whom. With the correct interface and education of the risks, the underlying platforms are very capable of working for vulnerable populations. Specialized websites for people with developmental disabilities have been preferred partially for their perceived increased safety, but this may be more due to the smaller target they represent rather than any fundamental improvement in security.

Risk Management and Peer Support

Community living service agencies have been stepping up their efforts to implement risk management procedures to help reduce the vulnerability of people with disabilities. Kendrick (2005) suggests that developing such safeguards can be quite challenging when one considers that "the dangers to be protected against involve persons who will conceal their true intentions and conduct both before and after the fact" (p. 9). However, he also acknowledges that such challenges can be mitigated if they are met with a "conscionable amount of vigilance" (p. 9).

To this end, Kendrick (2005) proposes that vulnerable people may want to consider having someone with them when they vet people interested in entering their lives. In the context of social media, this support could come from an online "buddy" whom they could contact whenever they were unsure about an incoming request or message. Ideally the buddy would be a social media savvy self-advocate or sibling (rather than a parent or caregiver). Such a peer-based buddy system would be activated at the full discretion of the user, thus adhering to Kendrick's principle of self-direction, avoiding unnecessary surveillance, and encouraging a peer support group in line with the principles of social media.

The nature of communication on social media, where most posts are visible to the group or public, can provide an inherent safeguard and feedback opportunity. By having a user's posts visible to some or all of a person's other friends, (including family, service providers, self-advocacy group facilitators, people with and without disabilities) opportunities exist *naturally* for others to help in distinguishing strangers from friends, recognizing risky communications, and providing coaching around appropriate content.

■ Survey and Consultations

Introduction

To further explore issues raised in the literature review and to gain more insight into the current use of computers and social media among people with developmental disabilities, CanAssist conducted a survey and organized several focus groups. The following section provides a detailed summary of our research methodology, findings, themes, and analysis.

Survey Description

Background

As part of this project, CanAssist conducted a survey of people with developmental disabilities and supportive others (in situations where the people with disabilities were unable to complete the survey themselves) to investigate their computer and social media habits.

Paper versions of the surveys used are attached to this report (Appendix A – Survey Questions for Person with a Disability and Appendix B – Survey Questions for Family and Caregivers). The same survey was delivered online through Survey Monkey.

Methodology

- This survey was conducted both in paper form and online (through SurveyMonkey.com) within British Columbia and elsewhere in Canada by CanAssist from October 22 to December 10, 2010.
- Total respondents: 214 people¹⁷ (+ 37 rejected¹⁸).
 - Parents/Guardians: 84
 - Care Workers: 62
 - Self-advocates: 29
 - Self-advocates with help: 20
 - Friends: 10
 - Family Members: 9

¹⁷ To request raw survey data, please contact info@canassist.ca

¹⁸ Responses were rejected for one or more reasons:

- no social media questions answered
- location or age range of person with disability unknown by respondent
- computer use/autonomy of person with disability unknown by respondent

Methodology (continued)

- The self-selecting sample was drawn from a number of sources.
 - National Family Conference, "Families, a Journey of Generations Moving Mountains" in Whistler, BC on October 22-24, 2010
 - A broadcast email message sent to Community Living BC, other community living agencies in BC, youth groups in the Greater Victoria area, and to the Association of Community Living in other provinces. Recipients of this email message were asked to forward it to their own networks
 - Focus groups representing CLBC's Provincial Council and four of its community councils (Upper Fraser, Surrey, Central and Upper Island, and South Island), four Victoria groups (two for self-advocates, one for under-18 youths, and one from the Ozanam Centre), and one Surrey self-advocate group.

Limitations

- Given the voluntary nature of the survey and the fact that the vast majority of participants completed the survey online, there was likely a selection bias towards those with more interest in and/or experience with social media.
- For persons with disabilities who independently completed the survey, the nature of the survey (text-based) biased the result towards persons that have the required literacy and computer skills to independently complete a survey in this format.

"Again, you design your questions for higher functioning individuals who can answer most of these questions; individuals who are limited because of mobility or communication problems are overlooked" – Parent surveyed

- People with disabilities living in the Vancouver/Fraser region were under-represented in the sample—29% of the sample vs. 60% of the BC population—while Vancouver Island was over-represented - 42% of the sample vs. 17% of the BC population (BC Stats, 2010b). This may be due to the fact that CanAssist is located in Victoria, and those familiar with CanAssist locally were more likely to participate than those who lived elsewhere.
- Respondents under the age of 35 in British Columbia were over-represented in the sample: they represented 73% of the sample but constituted 42% of the BC population (BC Stats, 2010a).

Survey Findings

Note: n values vary by question, as most questions were not mandatory.

Age of People with Disabilities by Respondent Type

- Self-advocates (n=49) were more likely to be older than those who were being represented by a member of their support system (n=165). 71% of self-advocates were 26 years of age or older, and 66% of those being represented by someone else were under the age of 26.
- Parents (59%) were the most likely to represent people with disabilities up to the age of 25 (n=121) while self-advocates (38%) and care workers (35%) were the most likely to represent those who were 26 and older (n=93).

Prevalence of Disability by Type

- Literacy (53%) was the most commonly reported challenge for the people with disabilities represented in the sample (n=212). This was followed by attention (47%), learning (46%), and speech-related (38%) challenges.

“Social media is not useful for an individual who has limited literacy skills. The computer is used occasionally at Jigzone where a puzzle can be found, but assistance to access the site is necessary.” – Parent surveyed

- The least reported challenges were related to mobility (17%), sight (10%), and hearing (7%).

Computer Use by Region

- Of the people with disabilities represented in the sample who lived in either the Vancouver Island or Lower Mainland region (n=151), 90% used computers. Of those living elsewhere in BC (n=43), 72% used computers.

Reported Ability by Respondent Type

- 31% of self-advocates reported not having a disability, and 10% of support system respondents reported that the person for whom they were completing the survey did not have a disability.
- 74% of self-advocates (n=49) reported being able to operate a computer independently, and 44% of support system respondents (n=165) reported that the person with a disability in their care were able to operate a computer independently.
- 82% of self-advocates (n=49) reported that they used Facebook, while only 50% of support system respondents (n=165) indicated that the person with a disability in their care used Facebook.

Computer Technology and Social Media Use

- The rate of computer and communication tool use by persons with disabilities is shown in Table 1:

Age	Computer	Social Media	Email	Texting
All (n=212)	86%	71%	38%	22%
<35 (n=155)	95%	81%	43%	28%
35+ (n=57)	58%	42%	25%	7%

Table 1: Computer/communication tool use of people with disabilities in sample by age

- The two most common reasons why a person with a disability *did not* use a computer (n=30) included not knowing how (67%) and not being able to type words on the screen (57%).
- Twice as many computer users with disabilities (n=182) used computers for less than 1 hour a day (39%) than for more than 3 hours (19%).
- Of the people with disabilities represented in the sample (n=214), 56% used YouTube, 49% used Facebook, 5% used Twitter, and 4% used Tyze (Figure 7).
- 84% of computer users with disabilities (n=182) reported having a high-speed Internet connection in their home.
- 11% of the people with disabilities in the sample (n=214) reported having accessed the Internet via a smartphone.

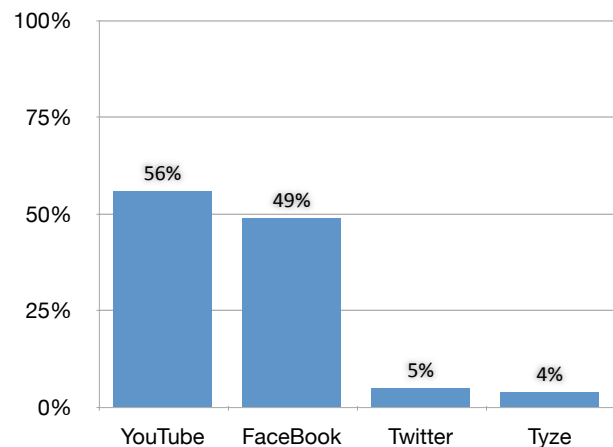


Figure 7: Usage of Social Media Platforms

Social Media Attitudes of Support System Respondents

- 89% of support system respondents who answered the question (n=126) felt that social media platforms were somewhat or very important.
- Of the support system respondents who answered the question (n=136), 48% indicated that significant or total supervision would be required in order for the person with a disability to use social media. 87% indicated that some level was required. Table 2 provides a breakdown of the reported degree of social media supervision required:

None	A little	A lot	Total	Unknown
11%	38%	29%	19%	2%

Table 2: Reported degree of supervision required for social media use (n=136)

Social Media Attitudes of Support System Respondents (continued)

“Supervision is needed with YouTube as sometimes my son finds inappropriate videos.” – Parent surveyed

“I think that social media is hard for folks with special needs, especially if there is a cognitive delay; they are easy prey for online predators. Some websites can be quite tricky and one click and you are involved or now in a website with inappropriate content. It's a new learning for them about what's safe on the Internet and education needs to be taught about the risks when using websites like this.” – Parent surveyed

“People have very different and varied connections within a community. Too narrow of a field hampers social growth, yet some protection is a good thing. Individual cases vary greatly.” – Parent surveyed

- Of the support system respondents who had an opinion on the subject (n=92), 48% felt that both mainstream and specialized (i.e. disability-tailored) social media platforms would be equally valuable to the people with disabilities in their care, 34% favoured mainstream social media, and 18% favoured specialized social media.

“Would prefer use of a mainstream site like Facebook but can see particular uses for groups like Tyze for some particular types of communications with specific people.” – Parent surveyed

“I believe that those with diverse needs are a part of the population and generic media is important to instill this into culture.” – Parent surveyed

Survey Analysis

Computer User Profiles

The people with disabilities represented in the survey sample belonged to one of three basic computer use categories: computer non-users, computer-only users (i.e. people who used computers but not social media), or social media users (i.e. people who used computers *and* social media). Figure 8 represents the distribution of survey respondents among these three categories.

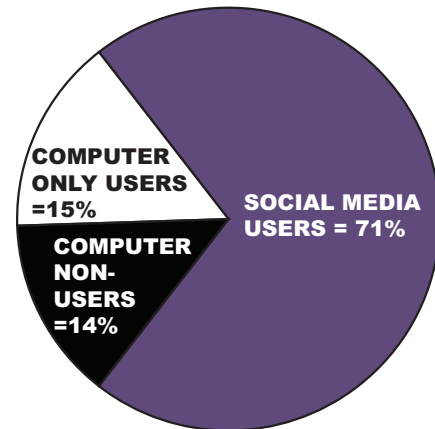


Figure 8: Distribution of Survey Respondents by Type of Computer Use

Social Media User Profiles

Respondents utilized social media to various degrees, governed primarily by their level of engagement and their level of independence when using computers. Based on these factors, the survey participants were classified into one of four groups: dependent observers, independent observers, dependent engagers or independent engagers, where independent engagers utilized social media to the greatest extent. Figure 9 represents a model of these social media usage patterns.

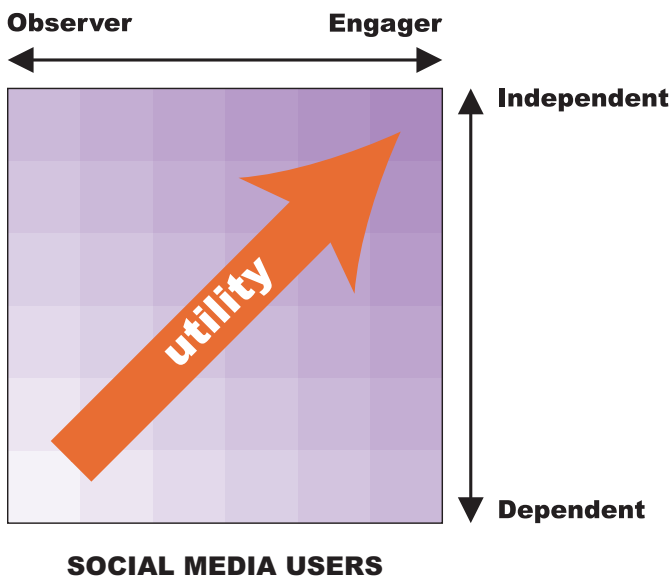


Figure 9: Social Media Usage Matrix

The people with disabilities represented in the survey sample were first determined to be either observers or engagers based on the social media they used. Observers were those who said that they only used YouTube, which is primarily used passively to find and view videos. Engagers, on the other hand, were the ones who indicated that they used Facebook, Twitter, and/or Tyze—websites primarily focused on active engagement, where users build networks of friends and a central activity is to send messages.

Social Media User Profiles (continued)

After being classified according to the particular social media websites they used, the people with disabilities were then subdivided according to their reported social media abilities. Dependent users included all those who said that they were *never* able to use the social media website(s) on their own without help from others. Alternatively, independent users were the ones who stated that they *always* used the social media website(s) on their own. In between these two extremes were the users who stated that they *sometimes* used social media independently, and they were deemed to be semi-independent users. Both factors (independence and engagement) describe a continuum, so it is natural that our two additional social media user groups – Semi-Independent Observers and Semi-Independent Engagers – are relatively large compared to those groups at the extremes (completely dependent and pure observers). Figure 10 shows the distribution of the people with disabilities from the survey according to which group they belonged to:

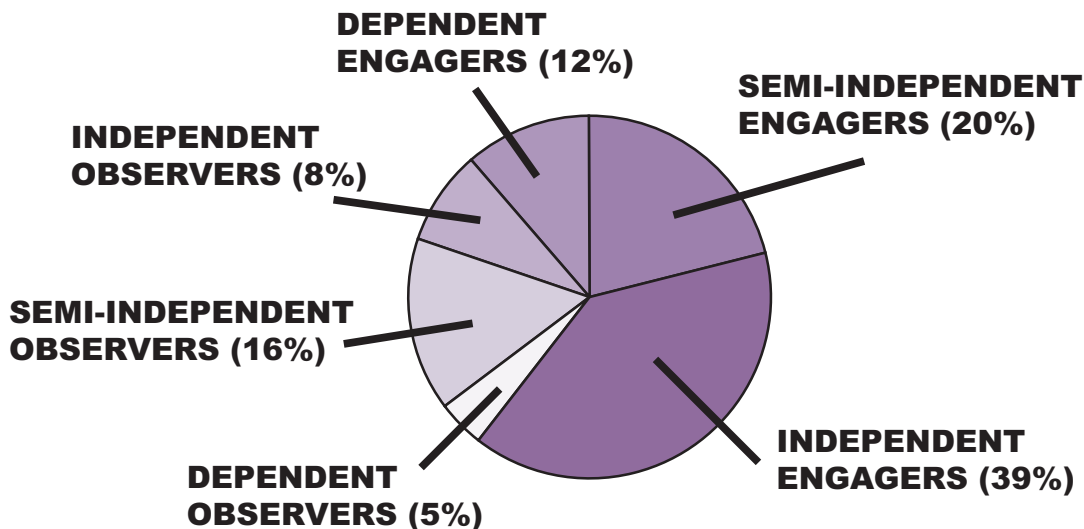


Figure 10: Distribution by Social Media Profile

Each type of user from the survey had unique characteristics that differentiated them from the other groups. The following section describes these differences in more detail.

Computer Non-Users (n=31)

Characterization: *Computer Non-Users* are older, live in a community setting away from their family, and have learning disabilities. They haven't had the opportunity to learn how to use a computer.

- 48% of their surveys were completed by a paid care worker.
- 77% of the people with disabilities represented in this category were 35 years of age or older.
- 47% lived outside the Lower Mainland and Vancouver Island.
- They typically had a literacy (68%) or learning (65%) challenge.
- They typically didn't use a computer because they didn't know how to operate one (67%) or because they couldn't type words on a computer screen (57%).

"I would not encourage my charge to use social media as he would not discern real friends from scammers/conners." – Parent surveyed

"As short-term memory deficits hamper reading beyond site-functional safety words, learning anything on a computer is challenging. Has had many simple computers but they don't last without mega support—usually broken in frustration. Does have a Wii game console but even that he only uses if prompted and supported." – Care worker surveyed

Computer-Only Users (n=32)

Characterization: *Computer-Only Users* have moderate cognitive disabilities and don't use social media websites because members of their support network either haven't given them much thought in regards to the person with a disability or believe that they wouldn't be safe for the person to use.

- Their survey was typically completed by a paid care worker (44%), and not by themselves (6%).
- The person with a disability typically had a literacy (63%), speech (59%) or learning (56%) challenge.
- 66% spent less than 1 hour/day on computers.
- 87% required assistance to use computers.
- 61% were able to move the mouse arrow on the computer screen, while 32% had no computer skills at all.
- 72% had a high-speed Internet connection at home and 13% had *no* Internet connection at home.
- If someone completed the survey on their behalf (n=30), 90% felt that the person with a disability would require significant or full supervision when using social media.

Computer-Only Users (continued)

- If someone completed the survey on their behalf and expressed an opinion on the subject (n=26), that person believed that social media websites were either somewhat (54%) or very (33%) important.
- If someone completed the survey on their behalf and answered the question (n=30), 47% did not know which type of social media (mainstream or specialized) they would prefer if the person with a disability were to use social media.

“I think what is called social media is typically anti-social and keeps individuals from pursuing the much more personal relationships needed for healthy living. They need face-to-face social contact and not the isolation of electronic communication.” – Family member surveyed

“If the people that I work with had their own computer, it would probably be used more—they use my own personal computer so their use is very limited.”
– Care worker surveyed

“I think many people with developmental disabilities struggle with reading and comprehension so using social media would be hard without support. Who will provide those supports? Will the government fund it? Will caregivers who are not paid for that task? Not likely. Supports cost money. More job coaching is needed...again money needed. Is sitting beside someone while they Facebook a friend money well spent? Hmm...I think that the general public at large would say no.” – Care worker surveyed

Dependent Observers (n=7)

Note: The number of respondents in this category is very low. These data should be reviewed with caution.

Characterization: *Dependent Observers* live with their parent(s), are dependent on others due to a communication and/or significant mobility challenge, and hardly use computers at all. Their parents are “lukewarm” to the idea of social media websites and use them as a passive form of entertainment for their child.

- 6 of 7 surveys in this category were completed by a parent/guardian.
- The person with a disability typically had literacy and speech challenges (5 of 7). Mobility challenges were also reported (3 of 7).
- 6 of 7 spent less than 1 hour/day on computers.
- All the respondents in this category required assistance when using computers.
- No respondents in this category had their own computer, and all but one used a shared computer at home.
- Of the 4 parents who expressed an opinion on the subject, 3 believed that social media websites were somewhat important.

Dependent Observers (continued)

“My daughter would most benefit from group visual online social interaction as she is dependent upon support to be involved in community and at times cannot leave our home. She also does not speak, and would most benefit from participation by seeing and hearing other folks. In addition, an online music/singing group would be fantastic.” – Parent surveyed

“The person I have in mind cannot talk, read or write, but enjoys watching YouTube videos. If he could learn something, even how to speak through this venue, it would be beneficial—YouTube with a purpose.” – Care worker surveyed

Semi-Independent Observers (n=24)

Characterization: *Semi-Independent Observers* are under 18 years of age, have low literacy skills, can operate a computer quite proficiently once someone helps them to get set up on it, and use computers with supervision to entertain themselves for a few hours each day.

- 54% of their surveys were completed by a parent/guardian, and 8% by a self-advocate.
- 71% of the people with disabilities represented in this category were 17 years of age or younger.
- 75% had literacy challenges, and 8% had significant mobility challenges.
- 17% used email, and 4% used texting.
- 54% spent 1 to 3 hours/day on computers.
- 29% operated a computer independently.
- 67% were able to type words on a computer screen.
- If someone completed the survey on their behalf (n=21), 100% felt that the person with a disability would require some degree of supervision when using social media.

“As parents we have chosen not to give our kids cell phones or allow them on Facebook or others like it. We believe in eyeball-to-eyeball conversations. Fortunately our kids are still young enough we can make that decision for them. When they are older a thorough understanding of how those websites work and the pitfalls of them will be discussed.” – Parent surveyed

“My kids only use YouTube to view cartoons, animal clips, entertainment suitable for young people. It requires constant supervision because she clicks indiscriminately and you never know what kind of garbage shows up. It can be fun, but it’s not used in any meaningful way.” – Parent surveyed

Independent Observers (n=12)

Note: The number of respondents in this category is low. These data should be reviewed with caution.

Characterization: *Independent Observers* are young adults who live with their parent(s), have attention and literacy challenges, can operate a computer fairly well on their own, and use computers with supervision to entertain themselves for a few hours each day.

- 50% of their surveys were completed by a parent/guardian.
- 75% of the people with disabilities represented in this category were 18 to 34 years of age.
- The person with a disability typically had an attention (75%) or literacy (67%) challenge.
- 58% spent 1 to 3 hours/day on computers.
- 64% were able to operate a computer independently.
- 82% were able to type words on a computer screen.
- If someone completed the survey on their behalf (n=10), 90% felt that the person with a disability would require some degree of supervision when using social media.

"I would be concerned about my daughter staying safe on the Web. She could get used to some rules over time. She has it firmly in her mind that Facebook is not safe - due to a presentation at her high school. My daughter is very social, but has to be prompted to phone friends and make dates to do things with them. She'd rather someone organize it for her!" – Parent surveyed

"My son is very sociable at times but I don't think he would use social media. He uses the phone and interacts with people in person. At home, he peruses YouTube a lot and plays video games. He doesn't have a real need to connect with friends - family contact seems to be sufficient." – Parent surveyed

Dependent Engagers (n=18)

Note: The number of respondents in this category is low. These data should be reviewed with caution.

Characterization: *Dependent Engagers* are adults who have a significant communication and/or mobility challenge that makes it very difficult for them to operate a computer, but the people who support them feel that social media websites are important and help them to keep in touch with friends and family.

- 28% of their surveys were completed by self-advocates.
- 65% of the people with disabilities represented in this category were 26 to 54 years of age.
- They typically had a literacy (71%), speech (59%), or significant mobility (35%) challenge.

Dependent Engagers (continued)

- 44% used email (of all the observer groups described earlier, 25% or less used email).
- 59% spent less than 1 hour/day on computers.
- 7% used computers independently.
- 6% were able to type words on a computer screen.
- If someone completed the survey on their behalf and that person expressed an opinion on the subject (n=12), 50% felt that social media websites were very important.
- If someone completed the survey on their behalf and that person expressed an opinion on the subject (n=13), 67% felt that both mainstream and specialized (i.e. disability-tailored) social media websites were equally valuable to the person with a disability.

“It would be great if Facebook were to design tools for people with disabilities. All in all, Facebook is awesome for my daughter as it gives her the opportunity to communicate with friends and family around the world. It gives her independence and the ability to say things she wouldn’t be able to communicate face to face (she is too shy and she doesn’t have the time to formulate answers/questions as she does in writing).” – Parent surveyed

“A non-verbal teen can be hard to talk to but when you have a glimpse of her life through photos on Facebook, it can make it a whole lot easier. I make sure to keep [her] Facebook filled with up-to-date photos of all the activities she is involved in. With over 200 friends, most from school, lots of her friends can talk to her about what she has been up to. It has worked really well for her. One of [her] favourite activities is to flip through other friends’ photos using a Jelly Bean switch. Facebook has also been a great place for friends to get in touch with [her] to make social plans: she had a friend coming in to town that planned to go to the Aquarium, she’s had movie plans made, an invitation to a Halloween party and a few more. Facebook works for [her] but it’s not a totally independent place for her to be.” – Parent surveyed

Semi-Independent Engagers (n=32)

Characterization: *Semi-Independent Engagers* are relatively young, have moderate cognitive disabilities, require a little help and some supervision to use computers for about an hour each day, and like to communicate with friends and family electronically.

- 80% were under the age of 26.
- 48% had a literacy challenge.
- 55% used email, while 26% used texting.
- 45% spent less than 1 hour/day on computers.
- 48% operated a computer independently.
- 76% were able to type words on a computer screen.

Semi-Independent Engagers (continued)

- If someone completed the survey on their behalf (n=26), 96% felt that the person with a disability would require some degree of supervision when using social media.
- If someone completed the survey on their behalf and that person expressed an opinion on the subject (n=18), 61% felt that both mainstream and specialized (i.e. disability-tailored) social media platforms were equally valuable to the person with a disability.

“I feel that having social media websites are an excellent source to communicate with family or friends from anywhere in the world!” – Care worker surveyed

“Social media is very, very dangerous for people with cognitive disabilities, and they should not be using it outside of strict supervision.” – Parent surveyed

Independent Engagers (n=59)

Characterization: *Independent Engagers* have mild cognitive disabilities, are quite literate, use mainstream electronic communication tools extensively without any help or supervision, and the people who support them feel that social media websites are very important.

- 45% of their surveys were completed by self-advocates.
- 24% had a literacy challenge, and 9% had a mobility challenge.
- 71% used email, and 52% used texting.
- 37% spent more than 3 hours/day on computers.
- 98% could operate computers independently.
- 89% were able to type words on a computer screen.
- 92% had their own computer.
- 24% had accessed the Internet with a smartphone.
- If someone completed the survey on their behalf and that person expressed an opinion on the subject (n=30), 60% believed that social media websites were very important.
- If someone completed the survey on their behalf (n=31), 90% felt that the person with a disability would require little to no supervision when using social media.
- If someone completed the survey on their behalf and that person expressed an opinion on the subject (n=31), 46% felt that mainstream social media websites were the most valuable to the person with a disability.

Consultation Description

Background

CanAssist held focus/discussion groups with self-advocates, families of persons with disabilities, caregivers, and persons with disabilities living in group homes. In total we reached 117 participants, including 60 persons with disabilities.

Methodology

10 focus/discussion groups were conducted in person within British Columbia from September to December 2010¹⁹.

- **Provincial Council, Vancouver**
12 participants (3 persons with a disability)
Largely unfamiliar with social media platforms and capabilities.
- **Self-Advocates, Victoria**
6 participants (4 persons with a disability)
Half the group was social media savvy, with knowledge of different platforms and awareness of privacy risks.
- **Self-Advocates for a Brighter Future, Victoria**
19 participants with a disability
Wide variety of abilities and social media awareness. Computer accessibility a significant problem for some participants.
- **Upper Fraser Community Council, Abbotsford**
7 participants (1 person with a disability)
- **Central and North Island Community Council, Parksville**
11 participants (1 person with a disability)
- **Self-Advocates, Surrey**
5 participants with a disability
2 were social media savvy, with advanced technical ability and awareness of specific risks, and the ability to take advantage of all the features.
- **Surrey Community Council, Surrey**
7 participants

¹⁹ A consultation was attempted at council meetings in the North and the Interior, however the meeting schedules at these councils did not allow time for a consultation on this matter during the consultation period of this study. Members of the community council were encouraged to complete the online survey in order to give their feedback on the issues.

- **South Island Community Council, Victoria**
13 participants (1 person with a disability)

- **Ozanam Centre, Victoria**
27 participants (23 persons with a disability)
Wide variety of abilities, with generally poor awareness of social media.
Computer use limited due to little opportunity for computer access.

- **Youth (under 18), Victoria**
5 participants (3 persons with a disability)
Significant physical disabilities, social media savvy.

Focus groups at community councils were conducted in the same format, with adaptations being made to reflect the needs of the audience and to focus in on emerging issues as the consultative process unfolded. Below is an overview of the typical focus group format:

1. **Introduction to social media**
A general introduction to social media, what is comprised within that definition, statistics on usage, and examples of popular social media platforms.

2. **Small group brainstorm of social media pros and cons**
Warm-up and examination of preconceptions about social media.

3. **Existing relationships and forms of communication**
How persons with disabilities are communicating currently, and the adequacy of these forms of communication.

4. **Privacy/Security**
A discussion of concerns around privacy/security on social media, as well as the tradeoff between supervision and independence.

5. **Mainstream and specialized social media**
A discussion around the value of accessible mainstream social media versus websites specialized for persons with disabilities.

6. **Review and update of social media pros and cons**
Review of initial positives and negatives, adding new ideas.

Consultation Themes

Awareness and Popularity

The level of awareness of social media platforms largely followed the expected demographic trends revealed in the literature review and survey, with older participants having very limited existing knowledge of social media, and younger participants being very aware of and engaged in social media.

“For the older generation, they don’t like it because it’s complicated to understand the basics” – Self-advocate consulted

The level of awareness was lowest amongst older parents, where it was often limited to being aware of the term and sometimes recognizing individual platforms that are mentioned in the media. This lack of awareness was cited as one of the reasons that persons with disabilities in their care were not being exposed to social media.

“I myself, not knowing how to use [social media], would not think of introducing it to them” – Parent/caregiver consulted

Similarly, for individuals who primarily receive services from agencies, a person’s experience with social media largely depended on the support provided and value placed upon technology and social media by the agency. Some individuals were living in group homes with either no computer or a computer that is locked in the office for staff use only. If these same individuals attend a day service that doesn’t build computer use into its program, their access is very limited.

On the other hand, some individuals living in group homes or home share have a computer set up just for the residents, or have a computer of their own. The care providers are willing and able to provide assistance to individuals with disabilities, including support in accessing and participating on social networking sites.

Amongst younger participants with disabilities who were able to access social media, it was a very popular activity. All participants in our youth focus group and most other social media users with disabilities cited Facebook specifically as one of their primary means of communicating with friends. Many parents expressed a similar sentiment, even if they themselves had limited experience. Social media platforms were described as “the wave of the future” for informal communication.

Importance of social media

The degree of importance that participants placed on social media did not appear to correlate to their level of knowledge. Some parents with very little existing knowledge of social media nevertheless ascribed a high importance to social media for the people with disabilities in their lives. Participants in general saw a lot of potential in social media platforms. Beyond being sources of entertainment and vehicles for casual communication, they were also seen as sources of information and as teaching tools.

Importance of social media (continued)

“It doesn't matter what people think about [social media], it's out there and it's going. Better to get on the train” – Parent/caregiver consulted

*“I think [social media is] good for them, it's good for those that choose to use it”
– Parent/caregiver consulted*

On the other hand, one caregiver of a large group of persons with disabilities with extensive personal social media experience was very negative towards its value to persons with disabilities, citing safety concerns and the inability of many persons with disabilities to use social media appropriately.

Communication

The power of social media to enhance and equalize opportunities for communication was a strong theme across all focus groups. Social media can provide access to everyone's opinion, not just that of journalists and those with the means to be published in traditional media. Social media can provide “a voice for those who have no voice elsewhere.”

*“We have a client that is totally non-verbal. He's been taking a computer course for 2 years and is just getting comfortable with the keyboard And wouldn't it be wonderful for him if he could communicate with his peers. It would be the first time he would be able to talk, and talk to anybody and everybody.”
– Service provider consulted*

When applied to persons with communication challenges, the potential of social media platforms to be effective means of communication was discussed in several groups. For non-verbal users, participants emphasized the flexibility of being able to compose messages using symbol-based input devices (i.e. PCS or Bliss symbolics) without the time pressures involved in face-to-face communication. On the other hand, as a parent and a caregiver pointed out, social media platforms have the potential to cause anxiety about being available to receive messages.

“She doesn't like to leave the computer in case one of her friends sends her a message while she's gone” – Parent/caregiver consulted

The multimedia nature of social media was also emphasized, especially by participants with disabilities. Participants valued the ability to share not only text messages, but photos, videos, and music as well. Participants with more acute disabilities (especially literacy) were more likely to be active on social media platforms focused on multimedia content such as YouTube, or photos on Facebook. However, interaction with these visual social media platforms was limited to passive viewing of content, rather than actively contributing new content.

Communication (continued)

For parents and caregivers, social media platforms were regarded as useful tools to stay informed about their children or persons with disabilities in their care. They were seen as good ways to connect, especially with people under the age of 35. This sentiment was mirrored by the 3 participants of the youth focus group who, when asked what media they preferred to use when communicating with people, all replied, "Facebook and the phone," with email being only used rarely.

"They won't answer their email for days but a Facebook message is returned right away" – Parent/caregiver consulted

Entertainment

After communication, entertainment was the most popular reason to access social media. Users described social media as exciting, fun, spontaneous, and creative. Higher functioning users took advantage of all the entertainment aspects of social media, including accessing and sharing music, videos, and playing games.

"I'm addicted to YouTube, I'm on it every week! I watch Brady Bunch"
– Self-advocate consulted

"One thing I like about Facebook is you can play games and stuff, and you can meet people on those games from all around the world"
– Self-advocate consulted

Entrepreneurial Activities

Three persons with disabilities cited entrepreneurial activities as reasons for accessing social media. One participant used Facebook to sell his homemade dog biscuits, while another sold artwork, and a third promoted their services as a public speaker using various social media tools. Some participants with disabilities felt that social media platforms provided good avenues to build a reputation online, which might be useful for future employment. This of course could also be detrimental, if the information one posted was objectionable to employers.

Isolation

The prevalence of isolation and limited social circles amongst persons with disabilities was raised in most focus groups. The potential of social media to provide an avenue for expanding social circles and overcoming geographic boundaries was recognized. For example, Facebook suggests new potential friends based on how many of your friends are already connected with those people. This provides a method of expanding one's social circle with some assurance that new contacts are safe (by asking existing friends about them). Self-advocates in particular used this method to expand their social circle.

Isolation (continued)

However, it was also noted that some people have such limited networks that they would not have anyone with whom to connect on social media.

"A person may want to get on Facebook, but their network is very limited"
– Service provider consulted

For people who had physical disabilities that complicated both travelling and their ability to attend meetings, social media platforms were seen as valuable tools to stay in touch with old friends, follow the adventures of travelling acquaintances, connect with family in other cities, or meet new friends.

"It makes you feel like you're part of life" – Self-advocate consulted

"I use Facebook because I connect with family, and see what my sister is doing"
– Self-advocate consulted

The group of Victoria self-advocates confirmed the idea of connection and collaboration by actively using Facebook to communicate with other self-advocacy groups in British Columbia.

"There are a lot of self-advocacy groups on Facebook from other places in Canada. I see what they're doing and talk to them" – Self-advocate consulted

It was recognized that tools like Facebook could contribute to someone's self esteem and sense of being valued, for example by having "27 happy birthdays" posted on their wall, whereas they might previously not have received any, or only been congratulated by their support staff.

Concerns were raised in several focus groups by parents and caregivers about whether increased social media use would come at the expense of face-to-face contact, which was seen as more valuable. The concern of overuse of social media platforms and the possibility for them to become addictive was widespread in focus groups involving parents of persons with disabilities.

"Who's going to be overlooking this whole thing to make sure there's this balance [between social media and other activities]." – Parent/caregiver consulted

Self-advocates also recognized this possibility, saying that you can "spend too much time on it," and that you had to know when to stop.

Demonstrating Goal Achievement

Community Living BC requires that individuals with disabilities receiving services and supports from accredited agencies set person-centered or quality of life goals for themselves. Many individuals develop these goals for themselves or with help from family and/or service providers. Social participation, interpersonal relationships and social inclusion are domains that are often considered in planning. Indicators of goal achievement might include increasing one's social network, friendships, social activities, groups one is a member of, and involvement in community life.

As discussed in detail at one consultation, social media platforms such as Facebook can be used to demonstrate outcomes achieved for people in these areas. For instance, Facebook provides information that makes it easy to quantify number of friends, contacts with friends, group membership, event invitations, events attended, number of in-person activities stemming from social networking, etc. Social media platforms can be used to provide evidence that goals related to reducing isolation and increasing relationships/friendships are (or are not) being achieved.

Privacy

The protection of privacy was one of the primary fears expressed by parents and caregivers, and by participants with disabilities who had experience with social media. For the most part, this was in regards to the privacy of individuals accessing social media, but some caregivers were also concerned about the privacy of other people appearing in photographs uploaded to social media.

While privacy issues were seen as applying to the general population, there was specific concern about whether persons with impaired judgment had the capacity to decide whether information should be made public or kept private.

“People want connection so badly; they could be putting themselves at risk”
– Service provider consulted

Some people may be too trusting, and thus share private information with people whom they do not know well. For example, it was suggested that users who share their home address and pictures of their belongings may encourage a thief to break in. Assessing whether a person with a disability was at risk on social media was seen as highly individual, and difficult to determine.

“It is problematic to assess that level of risk. It's a constant moving target for us”
– Service provider consulted

Privacy (continued)

Many participants, acknowledging that some individuals may require supervision when using social media, nonetheless felt that they were missing the technical supports necessary to provide that supervision. Although Facebook provides privacy controls that can be set to limit how much information is public, participants found them difficult to configure properly, sometimes requiring reconfiguration if the defaults were changed by Facebook.

“The controls aren’t there, and for someone who has a disability and may require support or supervision, how does that happen?” – Service provider consulted

Less dangerous, but also raised as a concern was the idea that some people may lose track of their “inner voice” and broadcast many inane updates to the world. This also applied to hurtful or angry posts, which were thought to occur more frequently on social media than in person.

One participant with a disability had heard about companies researching their job applicants on Facebook, and recognized that some of what her friends were posting could be detrimental in that situation.

“Employers are going on Facebook and they see this drunken guy with potato chips all over him” – Self-advocate consulted

Safety

Similar to concerns over privacy, the safety of social media users was a primary concern, especially for parents and caregivers. In addition to concerns over online bullying and sexual predators, participants expressed a wide array of concerns ranging from identity theft and computer viruses, to hackers compromising social media accounts. Some of these fears were attributed to the stories reported in the media about bullying or the posting of abusive content. In each group the discussion of safety inevitably led to the same rhetorical question being asked: *how does one protect a vulnerable population on social media websites?*

Countering the view that social media platforms were unsafe, some participants saw social media as also having positive safety effects. They felt that social media could provide a vehicle to monitor a person’s relationships online to a certain extent. They also believed that inappropriate content could provide teaching opportunities about acceptable sharing. One participant with a disability raised the idea that perhaps more communication could have helped in cases similar to the recent tragedy of a girl with Down syndrome being left with her dead mother for nine days before being found (CTV News, 2010). She mentioned that if this girl had been active on social media, perhaps friends would have noticed a lack of communication and notified the authorities sooner.

Safety (continued)

“It would be neat to have someone come in and have disability people learn to use a computer, So that if they do need help.. then.. you know.. they don’t have to be with a dead person for a week, they could be on the computer and try to get help” – Self-advocate consulted

Miscommunication and Misinformation

The potential for misunderstandings in text messages was raised in three Community Council focus groups. Since there is no feeling or emotion conveyed in the actual words of text posts on social media, people can misunderstand posts, possibly causing tension in relationships.

In addition, as there is no control or verification process on mainstream social media platforms, there are no guarantees about information shared on them. People can misrepresent themselves on these networks, and share information that isn't based in fact.

Accessibility

Participants had mixed feelings regarding the accessibility of social media. On the positive side, higher functioning users were able to learn how to use the mainstream websites fairly easily, with the large majority of independent social media users reporting that they were self-taught. In addition, participants mentioned that access to social media was relatively cost-effective. For home users, there were no costs beyond the purchase of the computer and Internet access; while for library users, access was even easier.

Beyond the physical access, people with literacy challenges saw the multimedia aspects of social media (sharing pictures and videos) as being helpful. However, a critical issue for participants was still access to computers, especially if the person with a disability was in services or living in a group home.

*“Some of our clients are higher functioning, but they don't have access to computers because the only computer is in the office and it's locked to them”
– Service provider consulted*

And for home users, while there may be a computer available, it would often not be equipped with the necessary accessibility software or input devices to be usable by the person with a disability. Cost was cited as a major reason for the lack of computer access, especially for persons on a limited income. One parent suggested that there was a real need for a program to refurbish older computers for people with disabilities.

Accessibility (continued)

If assistance was required, it was reported as not always being easy to find or customize for someone with a disability. One participant with a disability reported that while she was taking computer classes, the student-to-teacher ratio was too large in her class and she needed more individual help.

"Because of my learning delay, I need to have someone beside me, trying to calm me down, saying that I'm doing good... I need more one on one with a smart person that can do miracles with a computer" – Self-advocate consulted

Education was seen as lacking, but also not the whole solution for everyone with developmental disabilities.

"I think it's a tough one to say: let's have an education campaign and we're good and let's move on. I think it's an ongoing issue for every single individual. Some will master it, and some will never master it" – Service provider consulted

The accessibility of Facebook was problematic especially for people with vision impairments. One participant from the youth focus group was experienced with social media, and was able to use Twitter with the help of screen reading software, but had difficulty accessing Facebook.

"For NVDA (a screen reader), Facebook doesn't work so much, but Twitter is fantastic" – Self-advocate consulted

For another visually impaired participant, the inaccessible Facebook interface prevented him from using it independently. Even though he is a relatively sophisticated user—using Facebook to advertise his business—he requires an aide to navigate the complex Facebook interface.

"Things like Facebook are pretty big barriers because they have very complicated views" – Self-advocate consulted

For participants with more significant disabilities, the existing mainstream social media platforms were not accessible. Many caregivers reported that the people in their care did not have the ability to access social media due to limited literacy, an inability to use standard input devices like keyboards or mice, or an inability to understand the complex interfaces presented by mainstream social media tools. Even the more visual and simpler social media platforms such as YouTube presented problems for persons with alternative input devices (e.g. switch users).

Accessibility (continued)

Parents and caregivers without existing social media experience widely felt they did not have enough information to decide whether the people with disabilities in their lives should have access to social media platforms and, if so, how to introduce social media to them. Many parents and caregivers reported being too busy to learn how to use social media, and felt there was a lack of introductory materials to get started with social media. They felt there is a need to have plain-language manuals specifically geared towards using social media with people with disabilities.

Specialized Social Media

“While the concept of a separate site smacks of exclusion at first, the issue is not black and white” – Parent/caregiver consulted

The question of whether mainstream social media platforms or specialized platforms for persons with disabilities provide more value was difficult to answer for many participants. It was seen as a highly individual question, with specialized websites possibly being useful for persons with more significant disabilities, while mainstream access should be the goal for those capable of using them safely.

Awareness of specialized social media was extremely low; Tyze was the only specialized platform that some participants had heard of or used. No participants were aware of any of the specialized (and more accessible) social media platforms, so a comparison to mainstream platforms was impossible. However, for people with more significant disabilities, there was some consensus that a more moderated environment may be necessary.

“I think you would have to have a moderator, and that moderator would have to be really skilled at having set parameters for how the conversation is going to look like” – Service provider consulted

For many parents and caregivers, the concept of a separate platform was uncomfortable, and in conflict with the goal of integrating persons with disabilities into mainstream society.

“It's always preferable to first of all think about adapting what everyone else is using, because we are talking about inclusion, and inclusion is an attitude” – Parent/caregiver consulted

“I'm a bit torn about it we're all about using typical things, and yet we're relying on a product that is special.” – Parent/caregiver consulted

Specialized Social Media (continued)

In addition, one parent raised the issue that “convincing someone to get on a ‘special’ site might be a hard sell.” Several parents and caregivers stated that persons with disabilities in their lives were excited to access Facebook and other social media platforms because they knew that everyone else used these websites. Higher functioning participants with disabilities confirmed this, stating that they would rather use mainstream social media than anything that was specialized. For participants who were not able to access mainstream platforms because of physical access barriers, it was not possible to adequately explain how specialized platforms may be easier to access, so an informed choice was not recorded.

In general, participants felt that persons with disabilities were more interested in accessing mainstream social media. However, it was raised that in reality the population is very isolated. Users with similar challenges might be more likely to communicate with each other, making specialized platforms, or common interest groups on mainstream platforms, potentially valuable. One participant suggested that specialized platforms could function like training wheels for social media. The specialized website could be used to practice communicating over social media, learn about privacy issues, and develop computer skills, with the goal of eventually “graduating” to mainstream social media.

■ Key Findings

The Social Media Phenomenon

The fact that social media platforms, which have existed in their current configurations for less than 10 years, have already dethroned television as the most popular venues for media consumption indicates just how powerful they have become. A staggering 81% of Canadians aged 18-34 now have a social networking account. Our survey showed that 71% of respondents use social media platforms to some degree. For youth, social media platforms were cited as some of their most important means of communication.

Social Media Can Reduce Isolation

Social media platforms provide opportunities for people with developmental disabilities to meet new people and spend time with friends and family, which is especially important for individuals who may be isolated either geographically or due to the limitations of a disability.

Making the Connection

Social media platforms are far more effective when accessed through a broadband connection, which means that more than a third of Canadians are missing out. While 84% of the computer users surveyed reported having a broadband Internet connection, this was influenced by the selection bias in the survey. Smartphones are also quickly becoming the social media devices of choice, but the accessibility of these devices for people with disabilities is still sorely lacking.

Accessibility Barriers Overlooked

Social media accessibility research and solutions have largely focused on the needs of people with mobility- and vision-related disabilities, to the exclusion of people with developmental disabilities. Many caregivers reported that the people in their care did not have the ability to access social media due to limited literacy, an inability to use standard input devices like keyboards or mice, or an inability to understand the complex interfaces presented by mainstream social media tools.

Segregation By Design

When it comes to making social media accessible to people with developmental disabilities, the approach taken by many has been to create separate, specialized websites. For many parents and caregivers in the focus groups, the concept of a separate website was unpalatable, and in conflict with the goal of integrating persons with disabilities into mainstream society.

Custom Interfaces Hold Great Potential

With the release of their application programming interfaces, the large social media platforms have decoupled their regular interface from the data in their networks. This enables the creation of customized, accessible interfaces that have access to the same network of people while presenting a specialized graphical user interface. This means that people with disabilities may now be included in the mainstream communities of their peers without sacrificing their need for accessibility.

Literacy Matters

The most common type of challenge faced by the people with disabilities surveyed related to literacy, a challenge that negatively affected their ability to independently and actively engage in social media. Focus group participants with literacy challenges tended to limit their social media activity to the passive viewing of videos on YouTube or photos on Facebook, or be reliant on a support person to access social media.

A Digital Age Divide

The people with disabilities represented in the survey who were under the age of 35 were much more likely to use computers, social media, email, and texting than those who were 35 and older. The focus group consultations revealed a similar social media divide.

Light Computer Use the Norm

The largest contingent of computer users surveyed spends less than one hour per day on computers.

YouTube and Facebook the Most Popular

In terms of social media, the majority of the people with disabilities represented in the survey used YouTube, while just under half used Facebook. Facebook was by far the most popular platform for “active” social media users.

Social Media Supervision Required

Of those support system respondents who had an opinion on the subject, 87% indicated that some degree of supervision would be required in order for the person with a disability to use social media. It was identified that the tools to enable less intrusive monitoring or review were not available, and should be added to social media websites.

Social Media Diversity Desired

Of those support system respondents who had an opinion on the subject, 45% felt that both mainstream and specialized (i.e. disability-tailored) social media platforms would be equally valuable to the people with disabilities in their care.

Social Media an Equalizer

The power of social media to enhance and equalize opportunities for communication was a strong theme across all focus groups. Social media platforms were seen as an avenue for a traditionally marginalized population to make their voices heard.

Concern for Privacy

Fears over the privacy of user activity on social media have been on the rise ever since Facebook changed its privacy settings in 2009 to make users' posts, and some profile information, public by default. Several focus group participants echoed these fears, concerned that people with impaired judgment may not be equipped to decide what information should be made public and what should remain private.

Social Media Deemed to Have Importance

Eighty-nine percent of support system respondents surveyed felt that social media platforms were somewhat to very important. The majority of focus group participants shared this sentiment.

■ Recommendations

Primary Recommendations

- 1. Continue to demonstrate leadership in embracing social media, further research into social media issues for persons with disabilities, and encourage the use of social media platforms for communication.**

CLBC has demonstrated leadership in the area of social media access by developing a presence on Facebook, YouTube, and Twitter; providing Facebook groups for families and self-advocates to connect; dedicating resources towards support of these groups; developing social media educational materials; and commissioning this study.

We recommend that BC organizations continue to lead in this regard, with the intended outcome that contracted agencies and care providers will follow in the same direction, and people with developmental disabilities receiving services via agencies will benefit from increased social media access.

- 2. Create plain language educational and support materials about social media targeted at persons with disabilities, their families, and their caregivers.**

These materials should cover:

- a. A general overview of social media platforms, what they are, and how they are used.
- b. A high-level description and comparison of the most popular platforms.
- c. Acceptable behaviour on social media.
- d. How to safeguard privacy on social media.
- e. How to stay safe on social media.
- f. How to use the various social media platforms.

Ideally these materials would be available in multimedia formats, with the content from each section also available in video form, or utilizing graphics and pictures as an alternative to print as much as possible. Point “f” above should be delivered on a website in order to remain up to date.

3. Create or modify existing interactive social media safety assessment tools to assess users as to their knowledge and ability to operate safely on social media.

These tools should provide a simulated social media interface, and present the user with various scenarios (e.g. an incoming friend request, an inappropriate message, friends asking for private information, or uploading photos) and multiple options for how to respond. Incorrect answers (which put the user at risk) would be used as an educational opportunity to explain to them why certain things are inappropriate or dangerous.

After the session, a report would be generated on the results of each scenario and what skills need more work to safely use social media.

4. Develop an accessible Facebook interface, designed to address issues unique to persons with developmental and physical disabilities.

More accessible interfaces already exist for YouTube and Twitter; however, even though the developers' interfaces are well established, there is no solution for the most popular social media platform: Facebook.

An accessible interface should include some or all of the following features:

- a. Symbol-based navigation to assist users with literacy challenges.
- b. Text-to-speech option for all text content.
- c. Support for screen readers for visually impaired users.
- d. Support for alternate input devices such as low-accuracy pointer input, keyboard navigation, and switch scanning.
- e. Support for parent/caregiver configurable levels of oversight or review.
- f. Integration of a "buddy" system to leverage peer support for staying safe on social media, or allowing parents to provide some oversight of social media activities during the learning process.
- g. A simplified process for sharing multimedia content, such as photos or videos.

5. Undertake a pilot project to implement a buddy or support system around social media that would engage self-advocates and directly address concerns regarding security and privacy.

Focus group consultations revealed that some self-advocates already acted as mentors to their less social media savvy peers, taking pride in passing on their knowledge and education about how to stay safe on social media. This pilot study would support self-advocates in those activities with education, training and computer access tools, and evaluate the effects of increased access.

Secondary Recommendations

1. Develop an accessible survey tool for performing future qualitative surveys of people with developmental disabilities, especially those with literacy challenges.

Some of the selection bias in our survey may be due to the accessibility of the survey format itself. For participants to independently complete the survey, they would need significant literacy and computer skills, which excludes much of the target population. Current online survey tools are text-based and lack accessibility accommodations, which makes developing an accessible survey very difficult.

While other methods of consultation (focus groups, interviews, etc.) can reach this population, it would be advantageous for future studies to be able to reach a larger proportion of the population, including those with more significant disabilities. This would have value for annual user satisfaction surveys, demographic surveys, or accessibility surveys of this population.

A more accessible survey platform may include:

- a. Questions presented with multimedia approaches such as:
 - i. Text-to-speech
 - ii. Video recordings of someone asking the question
 - iii. Symbols, photos, animations, or diagrams to illustrate concepts
 - b. Alternate methods of responding, such as:
 - i. Selecting pictures or symbols instead of text answers
 - ii. Recording a user's response on video or audio
 - c. Support for assistive technology input devices
- ### **2. Continue conducting additional research into the effects of social media use by persons with developmental disabilities.**
- ### **3. Compile a comprehensive set of accessibility guidelines for websites to be usable by persons with developmental and physical disabilities.**

Many of these guidelines have already been established in the literature and in practical implementations, but the focus has been on physical disabilities and support with screen readers, to the neglect of considerations for developmental disabilities. What is necessary is a reference tool for non-experts in the field of accessibility to design accessibility into their websites.

4. Focus on the development of tools that provide users with the opportunity to more actively participate in social media.

While enabling access to the more passive social media tools has been a valuable first step, there remains a fundamental lack of access to social media platforms and features that promote more active engagement with social media. This is evident with accessible YouTube interfaces, which focus on presenting an accessible interface for finding and viewing videos, while omitting actively social features such as comments and video uploads. The key to equalizing access is to focus on technologies that enable active participation and content creation, rather than passive content consumption.

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■ Glossary

API – An Application Programming Interface is a way to interact with a software program for developers. For example, for social media it allows software developers to access the data in the network (a person's friends, messages, pictures, profile details, etc.) and present it in a different way.

CAPTCHA – Completely Automated Public Turing test to tell Computers and Humans Apart. This is a system to prevent unwanted advertising on webpages, by presenting a test that is designed to be difficult to solve by a computer, but easy to solve by a human.

User Interface – The part of a system with which the user interacts. A user interface is usually graphical on a computer, but may also be auditory (sound), tactile (touch), or a combination thereof.

JavaScript – A programming language that is used to make dynamic websites, where content can change at any time.

n – Sample size in the observation.

Social media – The group of applications and websites on the Internet where the majority of content is generated by users, and available for interaction by other users.

Social media platform – An implementation of social media. For example, Facebook, YouTube, and Twitter are each examples of social media platforms.

■ Appendix A – Survey Questions for Person with a Disability

This version of the survey is for the person with a disability to fill out. If the person with a disability cannot do the survey, please have someone else fill out the Family/Support Person Version instead.

Who is helping you to do the survey?

- no one is helping me
 - my parent or guardian is helping me
 - another member of my family is helping me
 - my friend is helping me
 - my care worker is helping me
 - I don't want to answer this question
-

Look at the map and tell us where you live:

- 1. Vancouver Island
 - 2. Vancouver Coast or Fraser Valley
 - 3. BC Interior
 - 4. Northern BC
 - outside BC
 - I don't know
 - I don't want to answer this question
-



How old are you?

- I am 17 or younger
 - I am 18 to 25
 - I am 26 to 34
 - I am 35 to 54
 - I am 55 or older
 - I don't know
 - I don't want to answer this question
-

**What is hard or impossible for you to do?
(You can pick more than one thing)**

- learn things
 - pay attention to things
 - read or write words
 - say words
 - see things
 - hear things
 - use my arms
 - none of those things are hard for me to do
 - I don't know
 - I don't want to answer this question
-

**How do you communicate with friends and family?
(You can pick more than one way)**

- we talk face-to-face
 - we send letters in the mail to each other
 - we talk on the phone
 - we send emails to each other
 - we talk through social media like Facebook
 - we talk through a video chat program like Skype
 - we text each other
 - I don't know
 - I don't want to answer this question
-

How do you usually use computers?

- I usually use computers without any help from other people
 - I usually use computers with help from other people
 - I don't use computers at all
 - I don't know
 - I don't want to answer this question
-

**If you don't use computers at all, why don't you?
(You can pick more than one reason)**

- I do use computers
- I'm not interested in computers
- I can't move the mouse arrow around the screen
- I can't type words on the screen
- I don't know how to use a computer
- I don't have a computer
- I have other reasons
- I don't know
- I don't want to answer this question

If you don't use computers, then you don't have to answer any more questions.

**What can you do on a computer without any help from other people?
(You can pick more than one thing)**

- I can turn the computer on
 - I can move the mouse arrow around the screen
 - I can type words on the screen
 - I can start the computer programs
 - I can't do any of those things without help from other people
 - I don't know
 - I don't want to answer this question
-

**What computers do you use?
(You can pick more than one)**

- I use my own computer
 - I use a computer at my home that I share with other people
 - I use computers at my school
 - I use computers at the library
 - I use a computer where I work or volunteer
 - I use other computers
 - I don't know
 - I don't want to answer this question
-

How many hours a day do you use computers?

- less than 1 hour a day
 - 1 hour to 3 hours a day
 - more than 3 hours a day
 - I don't know
 - I don't want to answer this question
-

Do you use YouTube?

- yes
- no
- I don't know what YouTube is
- I know what YouTube is but I don't know if I use it
- I don't want to answer this question

If you don't use YouTube or if you don't know, you can go to the next page.

Do you ever use YouTube without any help from other people?

- I always use YouTube without any help
- I sometimes use YouTube without any help
- I never use YouTube without help
- I don't know
- I don't want to answer this question

If you never use YouTube without help, you can go to the next page.

**What can you do on YouTube without any help from other people?
(You can choose more than one thing)**

- I can find videos
 - I can play videos
 - I can put my own videos on YouTube
 - I don't know
 - I don't want to answer this question
-

Do you use Facebook?

- yes
- no
- I don't know what Facebook is
- I know what Facebook is but I don't know if I use it
- I don't want to answer this question

If you don't use Facebook or if you don't know, you can go to the next page.

Do you ever use Facebook without any help from other people?

- I always use Facebook without any help
- I sometimes use Facebook without any help
- I never use Facebook without help
- I don't know
- I don't want to answer this question

If you never use Facebook without help, you can go to the next page.

**What can you do on Facebook without any help from other people?
(You can choose more than one thing)**

- I can find out what my friends are doing
 - I can tell my friends what I am doing
 - I can add pictures to my page
 - I can play games on Facebook
 - I don't know
 - I don't want to answer this question
-

Do you use Twitter?

- yes
- no
- I don't know what Twitter is
- I know what Twitter is but I don't know if I use it
- I don't want to answer this question

If you don't use Twitter or if you don't know, you can go to the next page.

Do you ever use Twitter without any help from other people?

- I always use Twitter without any help
- I sometimes use Twitter without any help
- I never use Twitter without help
- I don't know
- I don't want to answer this question

If you never use Twitter without help, you can go to the next page.

**What can you do on Twitter without any help from other people?
(You can choose more than one thing)**

- I can find out what other people are doing
 - I can tell other people what I am doing
 - I can add pictures to my messages
 - I don't know
 - I don't want to answer this question
-

Do you use Tyze?

- yes
- no
- I don't know what Tyze is
- I know what Tyze is but I don't know if I use it
- I don't want to answer this question

If you don't use Tyze or if you don't know, you can go to the next page.

Do you ever use Tyze without any help from other people?

- I always use Tyze without any help
- I sometimes use Tyze without any help
- I never use Tyze without help
- I don't know
- I don't want to answer this question

If you never use Tyze without help, you can go to the next page.

**What can you do on Tyze without any help from other people?
(You can choose more than one thing)**

- I can see what people write about me
 - I can tell my family and friends what I am doing
 - I can put pictures on my page
 - I can add things to my calendar
 - I don't know
 - I don't want to answer that question
-

What kind of Internet connection do you have at home?

- I have high-speed Internet at home
 - I have dial-up Internet at home
 - I don't have a connection to the Internet at home
 - I don't know
 - I don't want to answer this question
-

Do you ever use the Internet on a phone or something like a phone?

- yes
 - no
 - I don't know
 - I don't want to answer this question
-

In your opinion, how important is social media (like Facebook or Twitter) as a way of communicating?

- very important
 - sort of important
 - not important
 - I don't want to answer this question
-

If you have something else you would like to say, please write it here:

■ Appendix B – Survey Questions for Family and Caregivers

This version of the survey is for a family member, friend, or care worker to fill out. If the person with a disability can do the survey themselves (with or without assistance), please have them fill out the Person with a Disability Version instead.

Please tell us who you are:

- I am a parent or guardian
 - I am a family member
 - I am a friend
 - I am a care worker
-

Look at the map and tell us where the person with a disability lives:

- 1. Vancouver Island
- 2. Vancouver Coast or Fraser Valley
- 3. BC Interior
- 4. Northern BC
- outside BC
- I don't know
- I don't want to answer this question



How old is the person with a disability?

- 17 or younger
 - 18 to 25
 - 26 to 34
 - 35 to 54
 - 55 or older
 - I don't know
 - I don't want to answer this question
-

**What is hard or impossible for the person with a disability to do?
(You can pick more than one thing)**

- learn things
 - pay attention to things
 - read or write words
 - say words
 - see things
 - hear things
 - use their arms
 - none of those things are hard for them to do
 - I don't know
 - I don't want to answer this question
-

How does the person with a disability communicate with friends and family?

(You can pick more than one way)

- face-to-face
 - letters through the mail
 - phone
 - email
 - social media website like Facebook
 - video chat program like Skype
 - texting
 - I don't know
 - I don't want to answer this question
-

How does the person with a disability usually use computers?

- they usually use computers without any help from other people
 - they usually use computers with help from other people
 - they don't use computers at all
 - I don't know
 - I don't want to answer this question
-

**If the person with a disability doesn't use computers at all, why don't they?
(You can pick more than one reason)**

- they do use computers
- they are not interested in computers
- they can't move the mouse arrow around the screen
- they can't type words on the screen
- they don't know how to use a computer
- they don't have a computer
- there are other reasons
- I don't know
- I don't want to answer this question

If they don't use computers, then you don't have to answer any more questions.

**What can they do on a computer without any help from other people?
(You can pick more than one thing)**

- turn the computer on
 - move the mouse arrow around the screen
 - type words on the screen
 - start the computer programs
 - they can't do any of those things without help from other people
 - I don't know
 - I don't want to answer this question
-

**What computers does the person with a disability use?
(You can pick more than one)**

- their own computer
 - a shared computer at their home
 - computers at their school
 - computers at the library
 - a computer where they work or volunteer
 - other computers
 - I don't know
 - I don't want to answer this question
-

How many hours a day does the person with a disability use computers?

- less than 1 hour a day
 - 1 hour to 3 hours a day
 - more than 3 hours a day
 - I don't know
 - I don't want to answer this question
-

Does the person with a disability use YouTube?

- yes
- no
- I don't know what YouTube is
- I know what YouTube is but I don't know if they use it
- I don't want to answer this question

If they don't use YouTube or if you don't know, you can go to the next page.

How often do they use YouTube without any help from other people?

- always
- sometimes
- never
- I don't know
- I don't want to answer this question

If they never use YouTube without help, you can go to the next page.

**What can they do on YouTube without any help from other people?
(You can choose more than one thing)**

- they can find videos
 - they can play videos
 - they can put their own videos on YouTube
 - I don't know
 - I don't want to answer this question
-

Does the person with a disability use Facebook?

- yes
- no
- I don't know what Facebook is
- I know what Facebook is but I don't know if they use it
- I don't want to answer this question

If they don't use Facebook or if you don't know, you can go to the next page.

How often do they use Facebook without any help from other people?

- always
- sometimes
- never
- I don't know
- I don't want to answer this question

If they never use Facebook without help, you can go to the next page.

**What can they do on Facebook without any help from other people?
(You can choose more than one thing)**

- they can find out what their friends are doing
 - they can tell their friends what they are doing
 - they can add pictures to their page
 - they can play games on Facebook
 - I don't know
 - I don't want to answer this question
-

Does the person with a disability use Twitter?

- yes
- no
- I don't know what Twitter is
- I know what Twitter is but I don't know if they use it
- I don't want to answer this question

If they don't use Twitter or if you don't know, you can go to the next page.

How often do they use Twitter without any help from other people?

- always
- sometimes
- never
- I don't know
- I don't want to answer this question

If they never use Twitter without help, you can go to the next page.

**What can they do on Twitter without any help from other people?
(You can choose more than one thing)**

- they can find out what other people are doing
 - they can tell other people what they are doing
 - they can add pictures to their messages
 - I don't know
 - I don't want to answer this question
-

Does the person with a disability use Tyze?

- yes
- no
- I don't know what Tyze is
- I know what Tyze is but I don't know if they use it
- I don't want to answer this question

If they don't use Tyze or if you don't know, you can go to the next page.

How often do they use Tyze without any help from other people?

- always
- sometimes
- never
- I don't know
- I don't want to answer this question

If they never use Tyze without help, you can go to the next page.

**What can they do on Tyze without any help from other people?
(You can choose more than one thing)**

- they can see what people write about them
 - they can tell their family and friends what they are doing
 - they can put pictures on their page
 - they can add things to their calendar
 - I don't know
 - I don't want to answer that question
-

What type of Internet connection does the person with a disability have access to at their home?

- high-speed
 - dial-up
 - no Internet connection
 - I don't know
 - I don't want to answer this question
-

Does the person with a disability ever access the Internet through a smartphone or similar handheld device?

- yes
 - no
 - I don't know
 - I don't want to answer this question
-

If the person with a disability could use social media like YouTube and Facebook on their own, how much supervision do you feel they would need?

- total supervision
- lots of supervision
- a little supervision
- no supervision
- I don't know
- I don't want to answer this question

In your opinion, how important is social media as a way of communicating?

- very important
 - somewhat important
 - not important
 - I don't want to answer this question
-

Besides the social media websites that we asked about in this survey, what other social media websites does the person with a disability use?

There are social media websites made specifically for persons with disabilities. Which type of site would provide more value to the person in your care?

- a mainstream social media site like Facebook
 - a specialized site for people with disabilities (like Tyze)
 - both types are equally valuable
 - neither type would be valuable
 - I don't know
 - I don't want to answer this question
-

■ Appendix C – Author Information

Luke Melchior, DBA, has been involved in disability-related initiatives at both the local and national levels since 1998. Prior to joining CanAssist as Program Assistant, Luke was employed by Muscular Dystrophy Canada, where he developed disability awareness resources for schools.

Leo Spalteholz, BEng, is the Manager of Software Projects at CanAssist. He has been involved with CanAssist since 2004, developing software tools to support computer accessibility for persons with disabilities.

Robin Syme, MA, is the Assistant Director – Partnerships at CanAssist. Robin has considerable experience in establishing innovative partnerships such as Success by Six in addition to providing policy and program development leadership with respect to early childhood development, child care, public health, mental health, services and supports to children and youth with special needs, and adult community living.

Kristen Kay, BA, is involved in this study as a practicum student for a Bachelor of Social Work at the University of Victoria. She is Director of Quality Assurance and Practice at Becon Support Services in Victoria, and mentor to the self-advocacy group, Self Advocates for a Brighter Future.